STRESS, RESOURCES AND COPING PROCESSES

IN

CHRONIC CHILDHOOD ILLNESS

by

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FOR MY PARENTS,

RAJES AND D.V. MOODLEY

ABSTRACT

The present study investigates the stressors, resources, coping patterns, and associated variables among South African Indian families who had children suffering from chronic childhood illness, and a control group of mothers of children with minor health complaints. The coping strategies and self-esteem of the children were also examined.

The sample comprised 30 asthmatic, 22 leukaemic, 23 nephrotic syndrome and 30 control children and their mothers. The empirical measures used were the QRS, FILE, FIRM, CHIP, F-COPES, the Kidcope and the Self-Perception Profile for Children. Demographic and cultural information was also obtained using a biographical inventory.

All three illness groups experienced more stress than the control group, with the asthmatic group experiencing the greatest stress. There were significant differences in the management of resources, and in the use of coping patterns by the leukaemic and nephrotic syndrome groups. There were no significant differences between the asthmatic and control groups in the resources or coping patterns used. The chronically ill group experienced more stress than the control group, but used only coping pattern III significantly more. There were significant associations between certain

stressors and resources and coping patterns.

Children in the control group used the coping strategy of distraction significantly more than children in the chronically ill group. The chronically ill group used the social withdrawal strategy more than the control group.

Children's coping strategies were associated with family resource dimensions and coping patterns. Children in the control group displayed higher self-esteem on certain dimensions than children in the chronically ill group. The control group had higher perceptions of social competence and behavioural conduct than children in the three illness groups, higher scholastic competence than asthmatic and leukaemic children, and higher self-worth than leukaemic children. Certain self-esteem dimensions were significantly associated with children's coping strategies and self-worth. Additional findings related to family stress, resources, coping and adaptation were obtained. Additional data related to children's coping and self-esteem were also obtained. The results were discussed in relation to theoretical and practical implications for health professionals, as well as future research possibilities.

SUPPORTING SERVICES

In this research the statistical planning and analyses, and the recommendations arising from these analyses, have been done in consultation with the Institute for Biostatistics of the Medical Research Council.

DECLARATION

This study represents original work by the author and has not been presented for any degree at another University.

The research described in this thesis was performed in the Department of Paediatrics and Child Health, University of Natal, Durban.

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

Chronic illness in childhood exerts a profound psychological and social impact on the child and his family. The very diagnosis of chronic illness is said to "set the stage for a revolution in the way of life" (Mattsson 1972, p 183) of the child and family, with far-reaching implications as chronic disease affects every aspect of life. Changes occur in areas such as house-hold routine, schooling, recreation, transportation, financial planning and treatment, as well as hopes, dreams and ambitions. Relationships between the child and family members and those with the community are also affected (Barbarin 1990).

A chronic illness has been defined as a disorder with a protracted course which may be progressive and fatal; on the other hand, it may be associated with a relatively normal life span despite impaired physical and/or mental functioning (Mattson 1977). The illness may be present over a long period of time or have sequelae which interfere with daily functioning (Ireys et al. 1983). Schlebusch (1990) has defined chronic illness as a "disease ... characterised by structural, functional and biochemical changes ... a biological process in which the organs ... are affected" (p 41). Thus, the diagnosis of chronic disease in a child defines the child as being physiologically different, frequently requiring specialised attention. This broad

definition encompasses many chronic conditions. The prevalence of chronic disease is reportedly 10 per cent to 14 per cent, affecting a significant proportion of children in developed countries (Hobbs and Perrin 1985, Cadman et al. 1987, Gortmaker et al. 1990). Advances in medical technology have resulted in improved rates of survival in these children, resulting in an increased prevalence of chronic disease in the paediatric population (Ireys et al. 1983, Stehbens 1988, Waber et al. 1990, Gortmaker et al. 1990).

There are many diagnostic groups under the umbrella of childhood physical illness. However, every illness is a major stressor even though its symptoms and aetiology are unique to the specific condition. Differences may occur with treatment requirements, chronicity, the threat to life, prevalence among families, associated child and familial hardships, and so on. (Stein and Jessop 1982, Eiser 1990, Barbarin 1990, Barden 1991). Consequently, the specific nature of a family's task in integrating illness requirements into their life differs greatly among illnesses and may vary within a given illness. Yet irrespective these differences, every family must cope with such stressors as the allocation of emotional resources to ill and well members, sharing of responsibilities concerning the treatment regimen, managing transactions with medical personnel, coping with hospitalisation and anxiety concerning the child's vulnerability (Vance et al. 1980, McCubbin and Thompson 1991). Hence, chronic childhood illness engenders considerable stresses, not only on the child but on the entire family.

The variation of psychological responses in children to prolonged illness has been a task of medical, psychological and sociological disciplines for decades. It is vital to understand the effects of illness on both the family and

child (Eiser 1990). Therefore, it is pertinent to identify factors which contribute to adequate adaptation in families experiencing chronic illness, in order that appropriate intervention programmes be developed by health personnel, teachers and supportive service providers (Spirito et al. 1989, Venters 1981, Brantley et al. 1981).

1.2 Underlying Assumptions and Rationale for the Investigation

In constructing an approach towards examining the psychological responses of families and children to illness, several theoretical assumptions have been considered:

- The mind and body are presumed to be an interactive unit, where the body is a "biopsychosocial entity" (Engel 1977, Levy and Nir 1980, Schlebusch 1990).
- A theoretical paradigm and variables (stressors, resources, coping and self-esteem) for the assessment of child and family adaptation are considered.
- The child is viewed within the contextual framework of an interpersonal system, most significantly the family.
- The concept of "developmental lines" (vide infra) and a developmental approach is applied.

Chronic illness has been regarded as a biopsychosocial stressor. In other words, chronic illness is perceived as a stressor to the mind-body unit. In this context, stress is viewed as comprising three components: physiological, which refers to the body's physical response to all illnesses (Schlebusch 1990); cognitive, which refers to the subjective appraisal of stress (Lazarus 1975); and environmental, which

refers to stressful life situations (Rahe 1975). The effects of these three components on adaptation to illness are comparable (Haggerty et al. 1975). In acknowledging illness as a biopsychosocial stressor, the "physical disturbance . . . will create an imbalance in the body's homeostasis and upset not only its equilibrium . . . but also interfere in its maturational and growth processes. These disruptions will then have an effect on simultaneously evolving intrapsychic and psychosocial processes. Once interfered with, these systems will in turn influence the original disturbances, creating a feedback mechanism that often augments the original conflict" (Levy and Nir 1980 p 341). The extent to which this cycle of debilitation or enrichment influences the child's global functioning depends on many factors. These variables may include type of illness, age at onset, phase of illness, severity and prognosis. The child's ability to comprehend the illness, his personality and process of development, and the interactive effects of the environment on the child are also important (Johnson 1985, Eiser et al. 1992).

Illness as a stressor holds the potential for psychological growth as well as dysfunction. Stressful family situations may serve as fertile soil for the development of creativity in families free of psychopathology (Bateson 1972). Hence, the biopsychosocial response of an individual is held to be adaptive, where "adaptation does not mean either a total triumph over the environment or total surrender to it, but rather a striving toward acceptable compromise" (White 1974 p 134). This implies that certain responses or behaviours are adaptive and may lead to varying degrees of adjustment by the person and/or system (Caplan 1981, Thoits 1986).

However, a gap still exists within the area of chronic illness and family research. As succinctly stated by Fromma

Walsh (1983 p 32) "the major question that lies ahead for theory building and research is this: Why are some families better able than others to cope with stress, and why do some even become stronger through the experience?" To address Walsh's question, it would be necessary to specify an area of stress, such as chronic illness, and to delineate how various families respond. Differences can be determined between those families which adapt successfully to the chronic illness and those that do not (McCubbin and McCubbin 1987, Wallender et al. 1989a, Wallender et al. 1990).

The family is perceived as a recipient of the stress inherent in the presence of a chronic illness and as a vital force that may act to ameliorate or exacerbate those stressors (Masters et al. 1983). Certain types of familial functioning occur in response to the tasks demanded by the illness (Garmezy and Rutter 1983, McCubbin and Comeau 1991, McCubbin 1991). It is surmised that management of available resources and patterns of coping are important in mediating the adverse effects of the illness on the child and the family. A successful negotiation of these tasks may follow from the development of such creative skills within the family.

In pursuing a family system perspective, it is believed that a child with an illness acts within a dynamic family unit, interacts with all members, and affects and is affected by this structure (Kazak 1989). Therefore, any change in the child would affect other family members significantly. The mother is considered the most representative member of the family unit in this investigation. An important reason for the selection of mothers is that they bear the greatest responsibility, both functionally and emotionally when family members are involved (Bloom-Feshbach 1981, Barden 1991). This has also been displayed in the focus on the mother's role in adhering to the treatment regimens of their children

(Pless et al. 1972, Eiser 1990). Generally, fathers have been found to be less involved with the care of the chronically sick children and less knowledgable about the disease (Frank et al. 1991, Eiser et al. 1992).

The characteristics which most determine childhood adaptation remain unclear (Whitt 1984). Literature has acknowledged the importance of the family in the child's development (Minuchin 1974, Hetherington 1980) and adjustment (Burr 1985, Wertlieb et al. 1986). In the present context, it is felt that the extent to which a child successfully adapts psychologically to a stressor such as physical illness or disability is related to family involvement and adaptation (Hamlett et al. 1992). Therefore, it follows from assuming a contextual, interpersonal theoretical paradigm (eg. the resiliency model, McCubbin and McCubbin 1991) that the chronically ill child's development is affected by the family's functioning (that is, their perceptions of the stressor, utilisation of resources and coping behaviours) (McCubbin and McCubbin 1991). The significance of this approach is that it acknowledges the family's powerful position as a "context of socialisation and support" (Drotar et al. 1984) for the ill child, and it allows for the complex sequence of interaction between these variables within the family system.

Chronically ill children are confronted with a number of medically-related tasks and stresses specific to their illness (Barbarin 1990, Eiser 1990, Moodley Kunnie 1990) to which they must constantly strive to adapt. These stressors include dealing with painful symptoms and procedures, adjusting to hospitalisation, and establishing relationships with health personnel (Moodley Kunnie 1990, Bull and Drotar 1991). Many clinicians hope that children will "get used to" the stresses related to their illness (Barden 1991). However, empirical findings do not support this belief

(Paternaude et al. 1979, Katz et al. 1980). In the absence of medical information and appropriate emotional support (LeBaron et al. 1985, Koocher 1986), children may abandon active attempts to master the situation in favour of a more passive acquiescence to their illness. It is with "existing strengths and weaknesses that ill children face the kaleidoscopic series of events which can precipitate psychological distress, modify life-style, erode self-concept, and impair social relationships" (Heisler and Friedman 1981 p 78). Several researchers acknowledge that the child's adjustment to these developmental challenges, compounded by the challenges of illness, is in fact moulded by family styles of coping and adaptation (Wertlieb et al. 1986, Daniels et al. 1987, Stabler 1988). It is further hypothesised that children's responses to the stresses of their disease may influence the course of their illness as well as their adaptation to it. Therefore, the coping strategies used by children are seen as a powerful force, particularly with children of 8 to 12 years, whose development of self-esteem and identity tends to be dependent on the self-mastery skills and esteem by significant others in the child's life (Whitt 1984). The importance of documenting the spontaneous process of coping of chronically ill children has been emphasised (Spirito et al. 1989). Such studies would not only highlight the "typical problems that chronically ill children identify as difficult" (Spirito et al. 1989 p 4), but would reveal the coping strategies employed when confronted with the wide range of stressors encountered with the disease. This information also has the potential to provide clues to coping patterns which may be taught or enhanced in treatment programmes (Moodley Kunnie 1990). Hence, the present research is designed to assess the range of coping strategies used by children who experience a long-term medical stressor. Such strategies would be useful in understanding the coping processes of children who experience chronic illness. It may also facilitate an understanding of processes which contribute to childhood

psychopathology.

Illness crises, painful procedures and episodes causing temporary dependence on the family may result in an interruption of the child's growing independence (Garrison and McQuiston 1989, Harper 1991). This is an important aspect of the child's developing sense of mastery and competence (Barbarin 1990, Moodley Kunnie 1990, Harper 1991), and can threaten the developing child's sense of self-esteem, which remains a significant element in overall self-concept. It would be useful, therefore, to focus on self-esteem from within the broad range of psychosocial issues arising from the stress of chronic illness. Self-esteem development, noted repeatedly as a central task of childhood (Mack 1983) is recognised as a key motivational force in choice of coping behaviours (Coelho et al. 1974, Rosenberg 1979), and is an essential ingredient to successful adjustment in life (Alexander and Friedman 1980). High self-esteem is a personal resource that facilitates coping (Garmezy 1983). Accordingly, the task is "to achieve to whatever degree possible a stable and enduring sense of self-worth, or stated differently, to develop the assurance of protection against ... lowering of self-esteem" (Mack 1983 p 35). There is consensus that self-esteem is a critical factor in the differences in how children cope with illness (Rosenberg 1979, Cotton 1983). When functioning effectively, self-esteem serves as a protection against psychological onslaughts and as "an inner resource of comfort" during such an experience (Alexander and Friedman 1980 p 367).

The theoretical paradigm of "developmental lines" (Cotton 1983) assumes that normal childhood development, which is marked by a move from dependence towards self-reliance, always occurs within an interpersonal context and follows a progressive path. This path is distinguished by consecutive

phases which characterise certain stages from infancy to adulthood (Freud 1965, Cotton, 1983). Therefore, when studying self-esteem, this approach is useful in that it acknowledges the multifactorial process of the structuring of the child's self-concept. This includes the ongoing interaction of the individual's physical maturational process with his social and familial environment and the adaptational responses which continue throughout life.

Additionally, there appears to be a lack of consideration given to the developmental age at which chronically ill children have been studied (Kazak 1989). Nearly all childhood chronic illness studies are based on a broad age range, usually 6 through 18 years (Spirito et al. 1989). As there is a relative lack of information on the middle-aged child between 8 and 12 years, the present study will focus on this age group. This stage is characterised by the beginnings of logical reasoning, where abstraction is evidenced in the child's ability to simultaneously consider several features of a given situation, in this case, the stresses of chronic illness (Piaget 1929, Whitt et al. 1979). This may have implications in the choice of coping strategies and the self-esteem of the child.

Thus, although the generalised effects of chronic disease on family adaptation are not well understood (Eiser 1990), there appears to be a lack of research involving comparisons of the stresses and resource management of families across different disease groups. There is also an inadequate representation of studies involving comparisons of adaptation of children (that is, coping and self-esteem) with different chronic diseases (Eiser 1990). Few researchers have considered the implication of adaptation for the child and/or family, either in terms of disease-related behaviour or coping processes. The relationships between coping by families and/or mothers

and coping by children have also not been established. To the author's knowledge, the literature on stress, coping and chronic disease reveals an absence of research evaluating stress, resources and coping in mothers and children of the same family.

1.3 Definition of Terms

For the purpose of this research, the following terms are clarified:

- **Stressor**

A stressor is a life event or occurrence of sufficient magnitude to bring about change in a system (McCubbin and McCubbin 1991). It may be experienced by its impact on any of the members of the system or experienced in various areas of family life. The severity of a stressor is determined by the extent to which it threatens or disrupts stability, or places demands on the family's resources.

- **Demands Pile-Up**

A pile-up of demands is experienced by families with chronic illness. Families are frequently exposed to more than one stressor, as crises evolve and are resolved over time. Anxiety and fatigue are examples of pile-up which can occur with a single stressor (McCubbin and McCubbin 1991).

- **Family Crisis**

Family crisis has been defined as a continuous variable denoting the amount of disruption, disorganisation or incapacitation in the system (Hill 1949, Burr 1973, Lipman-Blumen 1975). Unlike stress, which is a "demand-capability imbalance" resulting in and characterised by tension (McCubbin and McCubbin 1991), crisis is a state of system disorganisation. Crisis is a transitional state in the family's effort to evolve and adapt by restoring stability to its prior level, or to a higher or lower level of functioning (McCubbin and MCCubbin 1991).

- **Family Vulnerability**

This is the interpersonal and organisational condition of the family system, and is determined in part by the pile-up of demands. This is a critical dimension as it applies to health and illness research, where families experience a piling-up of demands at the onset or impact of another stressor, or from a chronic stressor such as caring for an ill child (McCubbin and McCubbin 1991).

- **Coping**

Coping is referred to as a covert or overt effort by which an individual attempts to master a demand on the family system (McCubbin and McCubbin 1991).

- **Resources**

Resources refer to the broad range of reserves, social networks and aids which are potentially available in time of need (McCubbin et al. 1980).

- **Management**

Management refers to mastery, reduction, toleration or minimisation of the stressful situation, involving cognitive, affective and behavioural responses (McCubbin and Comeau 1991).

1.4 Proposed Investigation

The present study investigates the stressors, resources and coping processes among South African Indian families who have children with chronic illness. The study further examines the self-esteem and coping strategies of chronically ill children. For comparative purposes, the study also investigates these factors in a non chronically ill group of families and children. Children from three chronic illness conditions have been selected for the investigation, viz. asthma, leukaemia and nephrotic syndrome. These conditions are considered chronic health impairments (Gortmaker 1985, Hobbs and Perrin 1985).

1.5 Aims of the Investigation

The present study has been designed to evaluate:

- the patterns of stress experienced by mothers of children with a chronic illness;
- the resources utilised by families in the illness groups;
- the coping patterns employed by families in the illness groups;
- the differences, if any, in the patterns of stress, resources, and coping patterns of families in the illness groups and the control group;
- the coping strategies employed by children in the chronic illness groups in comparison with the control group of children who are not chronically ill;
- the self-esteem of, and its relationship to coping strategies employed in chronically ill and non chronically ill children.

1.6 Value of the Investigation

The present research will

- document the nature of stress and resources experienced by families with chronic paediatric illness;
- identify families-at-risk, so that the psychosocial sequelae of chronic illness could be minimised by providing more timeous psychological management;
- provide a study of coping processes which could provide information about intervention strategies

which may be applied to paediatric patients and their families;

- contribute to the literature of stress and coping in chronic illness by providing a comprehensive and systematic investigation of asthmatic, leukaemic and nephrotic syndrome children and their families;
- provide empirical data to support the development of effective intervention/care programmes for chronically ill children and their families.

CHAPTER TWO

A REVIEW OF THE RELATED LITERATURE

2.1 Chronic Illness and Life-threatening Conditions

The nature of stress experienced by families of children with chronic conditions varies with the type of condition (Frey et al. 1989, Wallender et al. 1990). It is important, therefore, that research on family adaptation to paediatric conditions consider characteristics that differentiate these conditions. It is also important to consider the relationship of these characteristics to the nature of stress experienced by the family (Kazak 1986).

In an attempt to increase our understanding of the nature of the medical conditions under study, this chapter will provide a brief descriptive analysis of asthma, leukaemia and nephrotic syndrome. Such information is essential in order to determine whether the pattern of functioning or adaptation may be generic in nature or whether the demands vary with the particular type of illness.

Asthma, leukaemia and nephrotic syndrome are conditions for which there are no known cures. Asthma is a disorder that produces occasional fatalities, while leukaemia and nephrotic syndrome are diseases with potentially fatal outcomes.

2.1.1 Asthma

Asthma is the most prevalent chronic childhood disease in Western countries (Kashani et al. 1988, Creer et al. 1988) and the most common chronic illness in White and Indian children in South Africa (Wesley, personal communication). Mortality is on the increase (Potter 1992). While asthma is common to all populations, rural communities in South Africa, previously not as susceptible to asthma, are now affected following urbanisation (Haus 1992).

This is predominantly a disease of early and middle childhood, its severity often tapering off in adolescence. The predisposition to asthma is frequently inherited (Haus 1992). It is a disorder of the respiratory system, characterised by hyper-responsiveness of the trachea, bronchi and bronchioles resulting in recurrent obstruction to the air passages.

2.1.1.1 Symptoms

Asthma is commonly manifested by cough and expiratory distress and, classically, by expiratory wheezing. Overt wheezing may not occur, and the major manifestation may be coughing (Creer et al. 1988, Kashani et al. 1988).

There are three characteristics pertinent to the condition (Renne and Creer 1985). Firstly, asthmatic attacks vary in frequency among children and in individual patients. A child may experience several attacks over a short period, and then be relatively well. There is considerable variability in the course of the disease. Some researchers have felt that

children "outgrow" the condition, but it has been found that such children may re-experience the condition in later life (Siegel et al. 1983). There is also confusion surrounding the prognosis of the condition. However, better prognosis is associated with earlier onset (Slavin 1977). Secondly, asthma attacks differ in severity from mild sensations of tightness in the chest, difficulty in breathing and mild episodes of wheezing to "status asthmaticus" (where there is extreme distress not relieved by routine therapy). This experience may vary among asthmatic children and also differ in the same child. It may also be hazardous as the child may become blue, unconscious, or even suffer cardiac arrest. Thirdly, children only experience distress during the attacks (McFadden 1980). They are well and their breathing appears normal at other times. Thus, the constant frightening experience to which both the parent and child is subjected may mean that such individuals are exposed to specific stressors to which they must adapt. It is surmised that children suffering from asthma and their families develop certain coping patterns through the course of the illness.

Those who suffer the more debilitating presentation of attacks acquire different expectations (Creer 1983a). Not only is there a greater reliance on daily medications, but the physical condition dictates their day to day activities (Renne and Creer 1985). Parents unwittingly develop a response set. For example, the family of a child who previously suffered only mild attacks may be totally unprepared to manage a severe one, may become petrified and "create an atmosphere of panic" (Creer 1979). They may continue to respond with fear and panic during subsequent episodes. Parents have also been known to respond with an over-protective attitude; for example, they may administer too much medication or hospitalise the child (Renne and Creer 1985). Exertion, play in grassy areas, cold temperatures and wind precipitate attacks and may also encourage maternal

over-protection of the child (Reed and Townley 1983). Therefore, certain inappropriate or maladaptive response patterns may affect coping and adjustment in the child and the family. This study attempts to examine how asthmatic children and their families cope with the stressors of the illness.

2.1.1.2 Psychological Issues

Among the frustrating features of asthma is the elusive nature of its triggering mechanism. Between 35 and 55 percent of asthmatic children appear to have an allergy or hypersensitivity to one or more substances which may act as triggering mechanisms; these substances include milk, eggs, dust, mites, and so on (McFadden 1980, Eiser 1990).

The theory of emotional causation has been widely cited, particularly in earlier literature (Harms 1963, Freeman et al. 1964). Psychoanalysts generally consider the cause to be at the unconscious level, with symptoms or attacks representing attempts at conflict resolution. It is believed that a disturbance exists in the mother-child relationship, where the child is insecure because of the mother's rejection, over-protection, inconsistency, rigidity (Harms 1963), narcissism on the part of the mother (Travis 1976), or conflict over achieving independence from the maternal figure (Freeman et al. 1964, Travis 1976). Behaviourists view the over-anxious mother as having rewarded her child during an attack by her solicitous behaviour, thereby conditioning the child to have more attacks. Stress theorists cite the hypothalamus as an agent, which upon receiving stimuli mediates the emotions physiologically via the adrenocortical route, thus precipitating an attack (Travis 1976).

Despite considerable attempts to understand the condition, asthma remains a complex and stressful respiratory disorder for both the physician and the child and its family. Irrespective of the origin, wheezing triggered by emotional stress carries the same risk as wheezing triggered by allergens (Creer 1982). Hence, an evaluation of the stress, resources and coping patterns of the families of asthmatic children could be utilised in designing behavioural programmes to reduce the stress associated with this disease.

2.1.1.3 Practical Implications

There are a number of lifestyle practices to which the families of children with asthma must adhere; (these may add to the stress of the medical condition). As asthmatic attacks frequently occur at night, a parent is required to be alert, sometimes causing tiredness and irritability. The child's diet may require monitoring as certain food products may have to be eliminated. Conditions may need to be modified to ensure that the asthmatic child is exposed to a "dust-free" environment (Eiser 1990, Weinberg et al. 1990), and to decrease the chances of contracting infections from other children. However, in a developing country such as South Africa, large families may inhabit crowded conditions resulting in an increased opportunity for contact with pathogens (Coovadia and Loening 1992). The use of coal and wood by disadvantaged communities may also increase the frequency of the attacks. Parental smoking may also need to be curtailed as smoke induces attacks (Klein 1990, Coovadia and Loening 1992). Other changes may include family relocation (which in itself is a life stressor) - away from coastal regions if the child is allergic to colds, or to a coastal area if the child is allergic to pollen. It is

likely that these changes to daily living styles will pose additional stressors for families of asthmatic children. Hence, it is necessary to investigate empirically the nature of stressors experienced by this group.

Early literature states that it is in its morbidity that the impact of asthma is most clearly seen, particularly in generating monetary costs (Creer 1979). In a study investigating financial stresses, Vance and Taylor (1971) reported that in the U.S.A. between 2 per cent to 30 per cent of a family's income was spent on managing asthma in one child. These expenses, of course, do not represent the total financial impact of the affliction. Other costs, such as special diets and lost work time, etc, must be considered as well. It may be surmised that these financial costs would be an even greater burden for families who are financially disadvantaged.

Activity restriction related to asthma has also been a leading contributor to school absenteeism (Hill et al. 1977). Frequent brief absences from school are more harmful to the academic progress of the child than occasional long absences (Creer and Youches 1971). Apart from conflicting reports on the relationship between asthma and poor school performance in children (Gutstadt et al. 1989), asthmatic children often find themselves excluded from many of the games and activities enjoyed by their peers, especially those who have furry pets (Weinberg et al. 1990). This may have negative implications for the child's personality development and ability to cope. Hence, a focus of the present study is the examination of the coping behaviour and self-esteem of children who have asthma.

2.1.1.4 Treatment

Modern medicine has limited the extent to which asthma interferes with normal life, and has reduced the incidence of episodes of associated ill-health and the likelihood of long-term complications. Asthmatics are treated with hyposensitisation injections or intermittent or continuous therapy, including steroids and beta-adrenergic bronchodilators (Coovadia and Loening 1991).

In view of the variation of physical and psychological responses in children and families to the stress of asthma, it is especially important to identify factors which may contribute to adequate coping and adaptation so as to encourage the implementation of effective intervention programmes by health professionals who work with this patient population. The present study, therefore, examines these important factors.

2.1.2 Leukaemia

In the area of chronic childhood disease, paediatric cancer has received considerable attention both in terms of research and public concern, despite being a relatively uncommon condition (Friedman and Mulhern 1992). In Western countries, cancer still remains the foremost cause of disease-related deaths in children below 14 years of age, and ranks fourth or fifth in Third World countries (Landsdown and Goldman 1988, Stehbens 1988, Silverberg et al. 1990, Coovadia and Loening 1992).

Although advances in treatment have resulted in significant improvements in survival (Travis 1976, Stebhens 1988,

Friedman and Mulhern 1992), the course of the illness is extremely variable, and many children have a series of relapses and remission.

Not all the treatment benefits are realised in developing countries. Factors such as the extremely high cost of treatment, delay in diagnosis and initiation of treatment, sometimes inadequate treatment, poor compliance and follow-up have been linked to poor socio-economic conditions (Coovadia and Loening 1992). Since South Africa has both Third and First World conditions, treatment and survival rates are predictably disparate.

2.1.2.1 Acute Lymphoblastic Leukaemia

Acute lymphoblastic leukaemia (ALL) is the most common childhood cancer, accounting for 80 per cent of cases (Stehbens 1988, Friedman and Mulhern 1992). It has a peak age incidence at 3 to 4 years (Sather 1986, Silverberg and Lubera 1987). The incidence is slightly higher in males (Coovadia and Loening 1992). Statistics at King Edward VIII hospital (the largest state hospital in the province of KwaZulu Natal) indicate that 24 South African children were diagnosed as having ALL between the years 1988 and 1990, with 17 cases diagnosed in 1991 (Coovadia and Loening 1992, Loening, personal communication).

Acute lymphoblastic leukaemia is a disease that originates in the bone marrow where blood cells are produced. The bone marrow produces lymphoblasts (malignant white cells) which make their appearance in the bloodstream and other tissue. The resulting lack of normal red and white blood cells creates the symptoms of this disease (Stehbens 1988). The

aetiology remains unknown.

Acute nonlymphoblastic leukaemia (ANLL) includes other types of leukaemia. These forms of leukaemia have a less favourable long-term prognosis than ALL (Altman and Schwartz 1983, Coovadia and Loening 1992).

2.1.2.2 Symptoms

Leukaemic children present with paleness and fatigue, prolonged infection, and haemorrhagic manifestations. These symptoms may be accompanied by irritability, weakness, low grade fever and localised and diffuse bone pain (Friedman and Mulhern 1992). Other features include enlargement of the spleen, liver, and lymph nodes.

2.1.2.3 Treatment

Improvements in the prognosis of childhood cancer are due to changes in the therapeutic modalities from single-agent chemotherapy to combinations of multiple-agent chemotherapy, radiation therapy, surgery, and to more aggressive supportive care (Jaffe 1987).

Treatment is typically conducted in three phases. The induction phase necessitates that drugs be administered to destroy malignant white cells and to return the body to normal haematological status. Freedom of signs of the disease, referred to as remission, occurs after approximately four weeks of induction therapy. The second phase includes central nervous system prophylaxis with cranial radiation

therapy and/or intrathecal medication (that is, into the spinal canal). Thirdly, maintenance therapy includes the use of different sets of drugs to prevent recurrences. Chemotherapy regimens vary, extending from two to three years.

The child's disease status is monitored by examining the blood, and by extraction of bone marrow and spinal fluid. The family are required to be alert for any signs of recurrence. Thus, a major dilemma facing the parents is the attempt to balance the amount of time and effort devoted to the disease and its treatment, against the amount of time devoted to the continuation of normal living (Spinetta 1982). If relapse occurs the established chemotherapy treatment is intensified and prolonged (Friedman and Mulhern 1992), with continual stressors.

Treatment means that ill children are subjected repeatedly to painful procedures (Stehbens 1988, Friedman and Mulhern 1992), sometimes developing a conditioned anxiety response. Anticipatory nausea and vomiting (ANV) (a maladaptive learned response) occurs in nearly one-third of children receiving chemotherapy. Therefore, it is necessary to examine patterns of coping that effect a positive adaptation in children suffering from leukaemia.

Thus, painful and emotional experiences are endured and become part of the child's life from the time of diagnosis, extending through his entire treatment. Research has focused on the relationships between cancer in children and emotional stress (Lansky et al. 1978), behavioural adjustment (Wasserman et al. 1987), and depression (Worchel et al. 1988). More cancer patients than controls display a tendency toward withdrawal, non-spontaneous behaviour, increased

awareness of physical vulnerability, and a propensity to worry (Deasy-Spinetta and Spinetta 1980). Such reactions in children with cancer are clearly the reactions of children under stress (Kellerman et al. 1980).

2.1.2.4 Side-Effects of the Treatment

Anticancer chemotherapeutic agents are used to interrupt the reproduction of cancer cells (Lilley 1990), damaging both malignant and normal cells. Side effects are highly distressing and may be life-threatening. Cells of various systems are killed, causing loss of hair (alopecia); cells of the mucous membranes are affected, with resultant nausea, vomiting, ulcers, change in taste perception, diarrhoea and malnutrition. Other side effects are headaches and double vision. The body's immunity is lowered, making the child susceptible to infections. Septicemia often occurs and there is a risk of death from haemorrhage. Despite modern therapy, a risk of permanent damage to various organs still remains (Coovadia and Loening 1992).

Radiation treatment has also resulted in adverse physical and neuropsychological effects (Meadows et al. 1981, Le Baron 1986).

The illness and its treatment also have psychological concomittants. During the first year of treatment, children may be absent up to four times the normal absenteeism rate (Stehbens et al. 1983b). This pattern may continue up to three years after diagnosis (Lansky et al. 1983), due to the ongoing parental concerns about exposing the child to infections, overprotection of the child, documented medical difficulties, frequent visits to the doctor and fears in the

child of peer teasing (Deasy-Spinetta and Spinetta 1980, Stebhens et al. 1983b).

It has been reported that such children experience academic failure (Wheeler et al. 1988), have difficulty concentrating (Deasy-Spinetta and Spinetta 1980), and have learning disabilities (Taylor et al. 1987). For example, children with leukaemia displayed a greater decrement in functioning on all WISC-R tasks than control children (Eiser 1980). They also exhibited impairment in neuopsychological functioning, particularly if the child had received central nervous system preventive treatment at an early age (Waber et al. 1990, Fletcher and Copeland 1987, Stebhens and Kisker 1984, Jannoun 1983). However, without some prophylactic CNS therapy, the likelihood of these children's long-term survival is reduced. The intellectual and neuropsychogical deficits must, therefore, be weighed against the issue of survival.

The rigorous treatment procedures over which the child lacks control, recurring hospital visits, the loss of privacy, increased symbiosis with parents, and fear of relapse may weaken previous childhood accomplishments. Leukaemia seems to be an illness that challenges all levels of self-worth, body-image, integrity, autonomy, and physical ability of the child, regardless of the outcome of the disease. Hence, it is necessary to ascertain the coping ability and self-esteem of this group of children in order that effective psychotherapy programmes be developed.

It is clear that a diagnosis of cancer spirals an array of medical, behavioural, social and emotional stressors for the child and his family. It is, therefore, important to establish factors which would contribute to the coping and overall adaptation of the leukaemic child and family

(Koocher, personal communication).

2.1.2.5 Remission

Children in remission fall into different categories, and are usually termed long-term survivors (Koocher and O'Malley 1981, Meadows et al. 1989, Mulhern et al. 1989, Speechley and Noh 1992). Remission is the period when the disease is under control (Friedman and Mulhern 1992). The child in remission usually feels well, which is paradoxical as the low white blood cell count necessitates isolation to prevent infection. A relapse necessitates the repetition of the entire treatment regimen.

During remission children and their families often "exist in an environment of chronic uncertainty," as the condition may recur (Matinssou and Cohen 1988 p 81). Ambiguity regarding symptomatic improvement or cure, and threat of death may interrupt their future goals (Kalnins et al. 1980). The existential experience may vary depending on the length of the disease process. Hence, the present study focuses on the examination of stress, resources and coping patterns of families, and the coping strategies and self-esteem of children during the induction (treatment) and remission phases of the disease.

2.1.3 Nephrotic Syndrome

Renal disease is not a single entity. There are many types of kidney disease where the presentation, chronicity and treatment vary. The concomitant psychological impact on the child and his family also vary with the stresses of each

disease.

Nephrotic syndrome is an uncommon condition in both Western and developing countries (Adhikari, personal communication). The aetiology of the condition in nearly all such children remains unidentified. It is a chronic relapsing condition characterised by massive losses of body protein through the urine as a result of kidney damage. The condition may be secondary to other medical conditions but is usually a separate entity, with a protracted course. The disease usually begins between one and four years of age and occurs twice as often in boys. The peak age incidence for Indian South Africans is three years (Coovadia et al. 1979, Coovadia and Loening 1992).

2.1.3.1 Symptoms

Nephrotic children display episodes of acute oedema, manifesting in massive swelling of the body, frequently grotesque shape, and a "moon" face, swollen feet and eyes (Loening, personal communication). The noticeable body changes may result in a poor body-image and poor self-concept in the child, and give rise to peer curiosity and ridicule. Hence, the present study focuses on the coping abilities and self-esteem of children with nephrotic syndrome.

2.1.3.2 Treatment

Children usually receive a short course of steroid therapy and antibiotics in an effort to control the condition. Management includes a high-protein diet and the use of diuretics. Exacerbations and relapses are characteristic of

the condition (Coovadia and Loening 1976).

Children who do not respond to steroid therapy are treated with medication which often has side-effects (Stehbens 1988, Friedman and Mulhern 1992). There is constant monitoring of the treatment as it can often cause more problems than the actual disease. Nonetheless, such drugs prolong the remission period which is characteristic of the course of this disease (Coovadia and Loening 1992).

Isolation as a treatment measure also has social implications as the child is expected to limit contact with other children so as not to contract infections.

2.1.3.3 Psychological Issues

There is scant psychological literature on children with nephrotic syndrome. However, it may be surmised that the emotional hazards experienced by children with nephrotic syndrome and their families are those seen in any serious chronic illness. Anxiety occurs in parents because of the insidious onset of the disease, and concern about the delay in diagnosis and treatment is almost universally experienced (Debuskey and Dombro 1970). Fear over the relapsing nature of the condition is experienced by all children and their parents.

The condition usually presents itself at the peak period of muscle development and activity. Testing and exploring these gross motor skills is an important function of any child's development. Unfortunately, the nephrotic child may experience limitations of activity as a result of his

physical illness and by exaggerated restrictions on the part of anxious parents. This has obvious consequences for developing self-esteem, autonomy and independence in the school-going child.

In view of the lack of adequate psychological information on children and families experiencing nephrotic syndrome, the present study attempts to provide an analysis of the stressors, resources, and coping processes in families, and the coping strategies and self-esteem of children affected by nephrotic syndrome.

2.2 Chronic Childhood Illness and Adaptation

Research on the psychological impact of chronic illness has lacked a coherent framework (Eiser 1990). Little attention was paid to the stress experienced, available resources, or coping processes of individuals. Much of the early literature in clinical psychology has focused on the impact of severely deforming defects on the development of the self (Pearson 1941, Niederland 1965). The paediatric literature on chronic illness focused mainly on epidemiological studies and medical and surgical management of children. It is only within the last two decades that research has been generated across disciplines, on the social, psychological and educational problems of chronically ill children and their families.

2.2.1 Chronic Childhood Illness, Stress and Resources

Although the concept of family stress has frequently been

utilised, it is often used without explicit definition. Most commonly, "stressors" have been defined as those life events of sufficient magnitude to bring about change in the family system (Hill 1949). Research on the subject has been plagued by conceptual and methodological difficulties. "Stressors" have not been studied independently of the dependent variables of family responses and adjustment (Simmons et al. 1973). While family stress may refer to the family's response to such events, the specific hardships associated with the stressor event have been ignored. As a result, interpretations of the relationship of a stressor to family adaptation have tended to be tautological. Nevertheless, researchers have classified stressor events and stress by the prevalence and intensity of the event, where stress involves the interaction of strain with other variables (Pearlin and Schooler 1978). On a more contemporary note, McCubbin and Patterson (1991) have utilised family life events to denote stress and family hardships.

As there is a little research on the stress experienced by the families of children with asthma, leukaemia and nephrotic syndrome, studies relating to different diagnostic groups will be drawn upon.

Holroyd and Guthrie (1986) administered the short-form Questionnaire on Resources and Stress (QRS-S) to investigate stress in three chronic disease groups, namely cystic fibrosis (N = 16), neuromuscular disease (N = 16) and a mixed diagnostic group (N = 11). A control sample was matched for age. The three groups presented with different patterns of stress, and demonstrated higher levels of stress than the control group. The neuromuscular group presented with a wide spectrum of problems, both quantitatively and qualitatively greater than the other two samples. Families of children with cystic fibrosis experienced extensive stress, while the

mixed group reported stress in only a few areas and were closest to the controls. It is necessary to note that the study focused on mixed samples in terms of ethnicity. Possible mental retardation in the neuromuscular group would also elicit different kinds of stress. The study was limited not only by the small sample size, but also by the use of the short-form QRS, whose validity is questionable.

The QRS-S was also used to assess the multidimensional nature of stress in families of children with cystic fibrosis (N = 23), diabetes (N = 24), moderate mental retardation (N = 24) and normal physical health (N = 24) (Walker et al. 1992). The results suggested that the families of children in the three diagnostic groups may be similar to families of healthy children with respect to the generic aspects of family stress. There were differences in the stressors specific to the child's disability. Again, a significant drawback is the utilisation of the QRS-S which has poor psychometric properties of the individual stress dimensions comprising the total scale (Holroyd 1979).

In a study assessing the functioning of parents (159 couples) of children with juvenile rheumatic disease, Timko et al. (1992) used two outcome measures of the Health and Daily Living (HDL) questionnaire (Moos et al. 1990) to measure mood, social activities and illness related coping; two outcome measures of the Family Effects of Illness scale (Stein and Reissman 1980) which were used to measure personal strain and mastery. The Family Resources index - an adaptation of subscales of the HDL and the Family Environment Scale (FES) (Moos 1974) - was used to measure cohesion, expressiveness and family arguments. The Child Health Assessment Questionnaire (Billings et al. 1987) was administered to measure pain and functional disability of the child. The results revealed that mothers reported more

depression than fathers. Poorer functioning of parents was related to the child's pain, functional disability and psychosocial problems. Access to more family resources was related to less depression in both parents. Illness-related avoidance coping was associated with more depressed mood and personal strain while approach or active coping was related to social activity and mastery. While these findings have potential value in revealing that family members are affected by the presence of a chronic childhood illness and that a coping pattern was identified, the measuring instruments appear to have been originally designed to tap other factors, and may, therefore, not yield reliable data.

Peri et al. (1991) utilised a modified version of Creer, Marion and Creer's Asthma Problem Behaviour Checklist, adapted to suit Italian conditions, and administered it to 84 parents of 42 preadolescent children with atopic symptoms (asthma, bronchitis, or hay fever) and 376 parents of 188 healthy children. While the children were not perceived as being affected by their illness, their illness undoubtedly influenced family relationships. Difficulties included disagreements over treatment, anxiety caused by the disease and the sacrifices made by family members. It is necessary to note, however, that the instrument measuring stress was limited to behaviour in a predominantly preadolescent group.

The above studies reflect little research on the stress experienced by families of children afflicted with asthma and leukaemia. There is a also a relative dearth of psychological research on children with nephrotic syndrome in southern Africa. The only known psychological investigation of this chronic condition has focused on its effects on the siblings of American nephrotic children. Vance et al. (1980) compared seventy-nine siblings from 36 families (each had a child with nephrosis) with seventy-nine healthy children from

closely matched families utilising the interview method, a parent rating scale, teacher's report, and a set of Self-Observation Scales (SOS) (Katzenmeyer and Stenner 1980). The major difficulties reported were in predictable areas such as financial burden; whereas for the siblings most problems related to social relationships. The findings, nevertheless, suggested areas of increased vulnerability for the families. Parents often denied the existence of apparently stressful events, but the personality profiles of the siblings suggested decreased social confidence and a lesser degree of self-acceptance. While this study represents an attempt to examine the impact of nephrotic syndrome on the family, it is restricted in that it focused largely on the study of siblings. Furthermore, it relied on self-observation and the interview method to obtain data, rather than on quantitative and standardised measuring techniques.

2.2.2 Chronic Childhood Illness and Family Coping

While the present consensus is to evaluate coping processes and adaptation in children and their parents (McCubbin et al. 1983, McCubbin and McCubbin 1991, McCubbin and Patterson 1991), there are few studies which focus directly on the identification of the coping processes used by families experiencing chronic disease. Much of the work in the area of chronic childhood disease is linked to defining correlates of 'good' or 'poor' coping. For example, Kupst and Shulman (1988) and Spinetta et al. (1981) relate 'good' coping in families to developing a philosophy of life, good family communications and good support systems.

An association between coping and family income, openness in communication, and satisfaction with medical care has been found with children who have cancer (Koocher and O'Malley

1981, Shulman and Kupst 1980, Spinetta 1980). Zeltzer et al. (1984a) point to the value of an open approach to discussing disease and treatment. Anxiety is not prevented by concealing relevant facts from children and, in fact, is likely to be exacerbated by incomplete or distorted communication (Spinetta et al. 1981, Nannis et al. 1982). Other variables such as emotional support (Morrow et al. 1984, Barbarin 1990), quality of marital relationship (Kupst and Schulman 1988, Lindhal and Markman 1990), positive approach (Obetz et al. 1980), and flexibility of family problem-solving (Krucia et al. 1979) have been associated with coping in families of children with leukaemia. Additionally, the variable of social support has been found to predict coping or adjustment (Billings and Moos 1981, Spinetta et al. 1981, Kupst and Shulman 1988).

In a study designed to ascertain family coping strategies, Venters (1981) measured family cohesion, satisfaction and communication in families (N = 100) with cystic fibrosis children (N = 129). A semi-structured interview and indicators of a quantitative family adequacy scale were employed. Two coping patterns - "endowing the illness with meaning" and "shouldering the burdens of the illness" - minimised stress and strengthened family functioning. While this study is valuable in terms of its approach and in identifying variables that families utilise, unfortunately it focuses on measures of family functioning, rather than actual coping strategies. Another criticism is that the children were not assessed.

Carswell et al. (1990) measured the relationships between the physical severity of asthma and the knowledge and feelings about the disease of the families of 86 asthmatic children. The parents' feelings of worry and fear, measured independently, were found to be related to their knowledge of

physical signs of the severity of asthmatic attacks. Although the families' overall knowledge was poor, they were apparently adjusting appropriately to asthma since they sought more information when they were worried. Brook and Shemesh (1991) found that chronic and prolonged asthma caused a decrease in communication between the parents and child, a potentially stressful area indicating the need for a comprehensive analysis of stressors experienced by families of children who have asthma. These two studies may also reflect how certain families cope with illness. The present research attempts to explore other patterns of coping.
A retrospective study was conducted on 30 German families, fifteen of whom had children in long-term remission and fifteen with children who had died of different types of cancer (Peterman and Bode 1986). A 42-item questionnaire was employed to evaluate perception of disease and to ascertain characteristics of coping styles. The results revealed that 10 per cent of the families perceived the disease as punishment, displayed denial of disease and exhibited family disharmony. More families saw the disease as a challenge and were, therefore, perceived as having coped. The study was limited since there may be different coping strategies which could occur with different kinds of cancer, and a target sample may well have disclosed a larger proportion of specific coping behaviours.

Kupst and Shulman (1988) evaluated how well 43 families of children with leukaemia were coping after 6 years in remission. Data on coping was obtained through semi-structured interviews, the Current Adjustment Rating Scale (CARS) (Berzins et al. 1975) and a staff-rated adaptation of the Family Coping Scale (Hurwitz et al. 1962). Results showed that these families made significant improvements in adjustment over time. Variables related to coping were the father's coping disposition, his occupational level, and family coping with earlier stages of the illness. Other

correlates of coping were: level of family support, quality of marital relationship, lack of concurrent stresses, and open communication within the family. It is necessary to note, however, that these families had more resources to begin with, a factor that undoubtedly affected the outcome. Most were intact families, with middle to upper class incomes. It is possible that families with fewer resources, and lower incomes may not adjust as well.

In their criterion validation study, McCubbin et al (1983) administered the Coping Health Inventory for Parents (CHIP) (McCubbin et al. 1983), and six sub-scales of the Family Environment Scale (Moos 1974) to 100 parents who had at least one child with cystic fibrosis. The results demonstrated a statistically significant association between parental coping and changes in the child's health (McCubbin et al. 1983). The coping efforts of both parents had a significant effect when directed toward maintaining social support, self-esteem and emotional stability (coping pattern II in CHIP). The mother's efforts to maintain family integration, cooperation and an optimistic definition of the situation (coping pattern I), were more effective according to measures of the child's health (viz. height, weight and pulmonary functioning). These results point towards the significance of what parents do to cope with illness. They provide useful information for health professionals and support networks interfacing with families who cope with chronic childhood illness.

Psychological adaptation was examined in 35 mothers of children with cystic fibrosis (Mullins et al. 1991). The instruments utilised were the Family Adaptation and Cohesion Evaluation Scales (FACES III) (Olson et al. 1985), Family Inventory of Life Events (FILE), (McCubbin et al. 1979), and the Escape-Avoidance subscale from the Ways of Coping Scale (WOC) (Folkman et al. 1985). Higher levels of maternal

distress were found to be associated with increased levels of stressful family life events, and an escape-avoidance coping style. Although this study was approached from a theoretical perspective (Wallender et al. 1989), it has been limited to the study of mothers and only one type of coping strategy. This study shall focus on different styles of coping by mothers and children from the same family.

2.2.2.1 Conclusion

A major drawback in the literature reviewed on stress and coping in relation to chronic illness is the absence of an accepted operational theoretical model which would enable predictions to be made or outcomes to be studied. There is also a lack of adequate definitions of the concept studied, leading to an inconsistency in measures utilised (Eiser 1990). Cross-study comparisons are, therefore, difficult. Control groups have not always been included. Also, many studies have been based on small, heterogeneous clinical samples which do not always allow for adequate generalisation of data. There has been little research on the stress experienced, resources and coping processes of families of children with asthma, leukaemia and nephrotic syndrome. Thus, "the total number of high quality studies being conducted with any single disease group is still very small" (Lavigne and Fabier-Routman 1992 p 149). Zimmand and Wood (1986) have suggested that the presence of specific types of stressors associated with different disorders merits further research. Hence, the present study attempts to provide a comprehensive analysis of the stress associated with three distinct medical conditions: asthma, leukaemia and nephrotic syndrome.

Researchers have also attempted to predict coping and adaptation to chronic illness by investigating a range of variables (Wallender et al. 1989). Other factors, such as coping patterns, play an important role in determining adaptation. Given that the range of functioning in families with chronic childhood illness is very broad, the most productive method for identifying coping processes and designing relevant interventions should focus on the identification of

- variables that predict adaptation within different clinical groups, and
- specific characteristics of the different illnesses that may contribute to increased stress.

It is important to explore and explicate the specific processes of adaptation in families with chronically ill children (Kazak 1989). Hence, the present research is designed to identify correlates or variables of successful adaptation by examining stress, resources and coping.

The present study also focuses on the different phases of the disease processes of leukaemia and nephrotic syndrome. Research is needed to assess if and how coping behaviours change during different phases of a child's illness and how this in turn affects coping and adaptation

2.2.3 Chronic Childhood Illness and Children's Coping

The identification of coping strategies used by chronically ill children has evolved as being an important area for study in the present investigation. The literature on chronic

illness in children has generally assumed that maladjustment is the consequence of a physical illness, and that children with chronic illness are at greater risk of psychological problems than are healthy children (Engstrom 1992, Wallender et al. 1988, Cadman et al. 1987, Walker et al. 1981, Lau et al. 1982, Eisen et al. 1980).

However, many of these studies were designed with the assumption that illness produces psychopathology and have revealed that illnesses with greater chronicity have more profound psychological problems (e.g. Drotar et al. 1981, Koocher and O'Malley 1981). The above studies focused on psychosocial variables (adjustment having been measured in many ways, for example behaviour problems, anxiety, depression, aggression etc), with an absence of focus on coping and adaptation by such children (Drotar 1981).

The belief that chronic illness implied maladjustment was challenged when Whitt (1984) emphasised multiple developmental and familial parameters which influence the adaptation of the family and child to illness. This led to the conclusion that individual adjustment is, in fact, based on the child's level of affective and cognitive development, his previous coping abilities, the psychological implications and meaning of the illness, as well as parental or family interactions (Barbarin 1990, Eiser 1990).

Lipowski (1970) holds the view that illness may actually promote psychological growth by presenting a constellation of adaptational challenges for the child. These challenges revolve around tasks of "defining the parameters and consequences of the illness and paediatric care phenomena" (Whitt 1984), thus espousing a new emphasis on coping and adaptation. Therefore, it should not be assumed that a child

will have an emotional adjustment problem simply because he has a chronic illness (Walker and Jacobs 1983, Tavormina et al. 1977). However, because an illness may be associated with psychological impediments to the quality of life and academic success (Walker and Jacobs 1983, Wallender et al. 1988, Koocher and O'Malley 1981, Eiser 1990), it would be useful to distinguish variables, if any, which are associated with adaptation.

In a notable study on the psychological adjustment of 117 families of children in remission with various malignancies, Koocher and O'Malley (1981) used a variety of measures including family interviews, the Combined Adjustment Rating, Vineland Social Maturity Scale, and parts of the Wechsler Intelligence Scale. Self-esteem was measured by a modified version of the Index of Adjustment and Values. While it was found that survivors of cancer were at higher risk for psychological difficulties than survivors of other non-life-threatening chronic illnesses, the data did not support the original hypothesis that cancer survivors would be overprotected and, therefore, socially, cognitively and emotionally retarded. This study was approached from a paradigm of coping and adaptation rather than psychopathology, and refers to the coping strengths of chronically ill children rather than their weakness.

More recently, Bull and Drotar (1991) assessed the coping strategies of children and adolescents aged 7 to 17 years (N = 39) in remission with cancer. A cancer-related coping interview (developed by McCabe and Weisz 1988) was incorporated into a Children's Stress inventory (Wertlieb et al. 1987). The children's perceived coping strategies were examined. When compared with school-age children, both male and female adolescents utilised more emotion management and less problem-solving coping strategies when faced with

cancer-related stressors. The study has limited generalisation since it focused on a very wide age range and on a small school-aged sample.

In a study of developmental differences in cognitive coping responses, Brown et al. (1986) administered an open-ended interview to children aged 8 to 18 years to elicit cognitive coping strategies in response to a hypothetical medical stressor (i.e. receiving an injection at the dentist), and a personal and imagined stressor. Raters assessed each child's primary cognitive response, and determined whether the responses were predominantly adaptive or maladaptive. Adaptive responses included positive self-talk, distraction, and thought stopping, while maladaptive responses included catastrophic thinking. The interrater agreement for the classification of the adaptive and maladaptive responses was 83 per cent. Furthermore, concurrent validity of the format was demonstrated by children whose responses were adaptive, having reported less trait anxiety (measured by State-Trait Anxiety Inventory) than children whose responses were maladaptive. However, it is necessary to note that the situational nature of coping precludes global labelling (Lazarus and Folkman 1984). Since few norms exist at this stage, one cannot label responses as normal or abnormal. Additionally, the assessment of an imagined stressor precludes the actual experience of a real stressor, and consequently introduces an artifact into the research. A further criticism is that a chronically ill group was not included in the sample.

Hubert et al. (1988) designed the Behavioural Approach-Avoidance and Distress Scale (BAADS) to assess the coping and distress behaviours of paediatric patients aged 3 to 11 years undergoing preparation for medical procedures. Coping was measured by the approach-avoidance subscale of the BAADS.

This was rated by observers during the phase of preparation. A significant relationship was obtained between behavioural coping and distress during preparation and the actual procedure. Here, coping was considered along a continuum of approach-avoidance. However, this dimension may be too narrow to fully capture the diversity of cognitive and behavioural strategies.

In a study of children's attempts to cope with stressful dental treatment, Curry and Russ (1985) observed the coping behaviour of dental patients aged 8 to 10 years. Children were questioned about the strategies they utilised during the dental treatment. They were observed at one minute intervals for three behavioural coping strategies. The children were also required to respond to a cognitive coping interview. The results reveal that every child utilised two cognitive coping responses and one behavioural coping response. However, the authors point to a number of limitations. These are: the cognitive coping interview, being a retrospective self-report measure, may not accurately reflect children's coping processes during the actual coping experience; the results were specific to the dental visit; the coping strategies have not yet been related to actual adjustment measures (Curry and Russ 1985). As only three behavioural strategies were assessed, the scale appears limited as well.

Lansky et al. (1975), in an earlier study, described the development of transitory school phobia in a small number of patients. This was interpreted as a way of coping with the overwhelming stress posed by cancer. It was felt that this symptom resulted in part from the parents' inability to cope with their own anxiety generated by the disease.

In a study assessing the coping patterns of a mixed-diagnostic medical population of children aged 10 to 18 years (N = 47), Spirito et al. (1988) administered the Kidcope, developed by the authors. Data analyses revealed that paediatric patients referred for psychological evaluation used social withdrawal and wishful thinking as coping responses. Girls with chronic illness used emotional regulation and social support more frequently than boys. Children who were coping reported that cognitive restructuring, blaming and distraction were more useful strategies. While this study represents one of the few studies which has attempted to identify specific coping patterns utilised by chronically ill children, the sample size is small, and the clinical group heterogeneous.

The above-mentioned studies have various limitations, including the sometimes unclear definition of the coping processes studied, small sample size, and lack of control groups. While there has been a limited number of studies investigating coping in children in relation to a medical illness, there is clearly a dearth of research studying the coping strategies of children suffering from the diseases of asthma, leukaemia and nephrotic syndrome.

In the face of increasing numbers of children surviving chronic illnesses which in the past were considered terminal, research in this area is essential if health professionals are to ensure successful negotiation of the turbulent and recurrent crises experienced by such children and their families. Identifying the patterns of coping and adaptation will assist medical practitioners and psychologists in advancing comprehensive care and intervention programmes. This would involve education of the child and family, along with the network within which they interface.

2.2.4 Chronic Childhood Illness and Self-Esteem

A review of the literature reveals few studies conducted on the effect of chronic illness on self-esteem or self-concept of children. (These two terms has been utilised interchangeably in the literature.)

Kashani et al. (1988) administered psychiatric inventories and the Child Behaviour Checklist to 56 asthmatic children (aged 7 to 16 years), and 56 matched control children, and their parents. The children also completed the Hopelessness Scale and the Piers-Harris Children's Self-Concept Scale. The study revealed that asthmatic children were no different to control children in self-concept. This finding is relatively consistent with other investigations using the Piers-Harris instrument to measure self-concept. For example, a study by Panides (1984) comparing the scale scores of children who had asthma with those of healthy children of the same age revealed no difference. Similar results were obtained by Rosenthal (1973). Taken collectively, these studies suggest that asthmatic children are no more encumbered with low self-esteem than non-asthmatic children. However, these studies were concerned solely with global self-esteem scores. An assessment of the different areas of competence, with which the present research is concerned, may yield different findings.

In contrast, in a recent study on the self-esteem of children with spina bifida, Appelton and Minchom (1993) utilised a psychosocial, medical and occupational therapy interview with 79 children aged 7 to 18 years. They found that most young people with spina bifida compare themselves academically, socially and physically with able-bodied peers, rather than

with physically disabled persons. The subjects perceived themselves as falling short in these areas. Adolescent girls were found to be at greater risk of low self-worth. Furthermore, Nelms (1989) examined the empathy, emotional responsiveness, depression, aggression and self-concept in 80 children with diabetes and asthma, and 40 healthy children (aged 9 to 11 years). The results suggested a similarity among ill subjects, who had higher levels of the characteristics examined. While asthmatics and diabetics differed significantly in self-concept, diabetics did not differ from healthy subjects in self-concept. A drawback is the reliance of the interview method, which may sometimes be subjective.

Hambley et al.'s (1989) study of children aged 5 to 16 years also revealed that most asthmatic children experienced behavioural and school-related problems, with 6 to 11 year old boys exhibiting global social competency problems as well. Girls were found to exhibit lower self-esteem than boys. Furthermore, a study of children attending a week-long camp-based psycho-educational programme for children with asthma, revealed that ill children displayed higher mean self-concept scores on the Piers-Harris Scale than the mean self-concept scores for the healthy standardised sample. It was suggested that the elevated self-concept scores of the subjects may have been due to a compensatory denial of some problems in order to maintain positive self-concept. A possible reason for the inflation of these scores may be related to the test used. Research has also criticised the Pier-Harris Scale for its single self-concept score (Harter 1985).

The above studies reveal variable findings regarding the self-esteem of children with chronic illness (Lavigne and Faier-Routman 1992). There remains a need for the

investigation of self-esteem in children who suffer from asthma, leukaemia and nephrotic syndrome. Such assessments should utilise sound measures designed to examine the different areas of a child's competence. The present study is, therefore, approached from this viewpoint.

2.2.5 Chronic Childhood Illness and Age and Gender

Most empirical work has not given adequate consideration to the child's developmental level in determining adjustment or adaptation to chronic childhood illness (Eiser 1990). Theoretically, age is a significant factor, and reference to this has been convincingly purported by Perrin and Gerrity (1984). As discussed in Chapter 1, at each stage of development the child must master certain basic tasks. Chronic illness in the middle childhood years may seriously hamper this ability. It was also suggested earlier that the skills available to cope with stress differ significantly as a function of age (Spivack and Shure 1985). The present research, therefore, attempts to study children between the ages of 8 and 12 years in relation to coping with the stressors of chronic childhood illness.

Despite the well-documented finding that males are physically more vulnerable than females (Gualtieri and Hicks 1985), and the data suggesting that boys display more adverse psychological responses than girls (Hurtig and White 1986), few studies have attempted to investigate the vulnerability and self-esteem of the two genders with chronic childhood disease (Eiser 1990). It has been suggested that certain medical conditions that reduce functional physical skills and general strength might produce greater social consequences for boys, given the athletic and activity-oriented nature of boys' peer contacts. Body size and visible facial deformity

are of concern to females (Harper et al. 1985, La Greca 1990, Harper 1991) Younger children also seem more affected in terms of school-related tasks and achievements (Allen and Zigler 1986, Rovet et al. 1987). Given these differences, the present study examines the self-esteem of males and females. As indicated earlier, such responses may also have important implications for the child's coping strategies.

Whiting and Edwards (1988) have even suggested that parents treat chronically sick boys and girls differently, where traditionally parents are more nurturing to girls. For instance, Walker and Zeman (1992) examined the effects of children's age and gender, and the type of the illness on parent's responses to their children's behaviour. They used the Illness Behaviour Encouragement Scale (developed by the authors). The results indicate that parents encourage children to adopt the sick role for more serious problems (for example, gastrointestinal symptoms) than for the common cold. Mothers also encourage children's illness behaviour more than fathers. Furthermore, girls receive more sympathy and are allowed more relief from responsibility during illness episodes than boys.

Traditional Indian families also tend to respond differently to boys than girls. The birth of a boy is regarded as a blessed event since boys carry on the family name, take over the duties as head of the family and are viewed as future breadwinners.

These differences in parental responses combined with the potential effects of the diseases may have important implications in the selection of coping strategies by boys and girls (Spirito et al. 1988, Spirito et al. 1992). The present study will, therefore, investigate the coping

strategies of boys and girls.

2.3 Theoretical Approaches

2.3.1 Theoretical Approaches to the Understanding of Stress, Coping and Adaptation

Conceptual and theoretical interest in the study of chronic illness adaptation have been rather limited. A review of the literature reveals various models on which adaptation of illness may be considered. These will be discussed briefly.

2.3.1.1 Model of Adjustment

Pless and Pinkerton (1975) have proposed a model of adjustment based on three factors, namely:

- intrapersonal, such as the child's premorbid personality, intelligence, social background;
- disease-related, such as chronic, severe, restrictive, etc.; and
- environmental, which refers to the attitude and perceptions of significant others, such as parents, friends, etc.

Adjustment is viewed as a dynamic process, continuing from childhood through adult life. Current functioning influences the responses of others, which in turn affects future functioning. Adjustment is a reflection of earlier cycles, and is subject to the influence of the child's inherent

attributes and psychological response to the illness. These attributes, including the response of significant others, determine self-concept and coping style. However, empirical work reveals that this approach has tended to concentrate on the influence of one set of variables on the child's adjustment, and has yielded inconsistent results (Walker et al. 1986, Perrin et al. 1989, Wallender et al. 1989). For example, there is little evidence that the disease parameters of severity and chronicity exert a simple effect on adjustment (Wallender et al. 1989).

2.3.1.2 Conceptual Model for Handicapped Children

Wallender and his colleagues have proposed a conceptual model (Wallender et al. 1990) to account for the differential psychosocial adaptation in chronically ill and handicapped children. A set of intrapersonal, interpersonal and socio-ecological factors may be defined:

- intrapersonal refers to the severity of handicap, functional independence and personality factors;
- interpersonal refers to temperament and coping style of the mother; and
- socio-ecological factors include marital and family functioning, family size and service utilisation (Varni and Wallender 1988, Wallender 1988).

While this model focuses on the potential reciprocal nature of these relationships, it does not differ very remarkably from Pless and Pinkertons' (1975) except in the details of the three factors. Families of chronically sick children are at great risk for maladjustment which relates to the increased risk of stressful situations to which they are

exposed (Varni and Wallender 1988). In this case, a taxonomy of problematic situations for the different chronic diseases needs to be defined. Active coping responses could result in a change so that the situation is no longer problematic, thereby producing positive consequences. However, the small numbers of chronically ill or sick children treated in any one clinic preclude evaluation with this model (Wallender et al. 1989). While there has been an attempt to assess this model with families of the handicapped (Wallender et al. 1989), and with those of children with cystic fibrosis (Mullins et al. 1991), research is still needed to develop this model with children of different chronic illnesses and their families to determine causal relationships (Mullins et al. 1991).

2.3.1.3 Family Functioning Model

In a further attempt at providing a model for illness and health, Haggerty (1968) has examined the relationship of family functioning and disease in the family on its members through "family diagnosis." Based on a general theory of family functioning, the model encompasses:

- past medical experiences and attitudes toward health;
- internal functions including relations to the family of origin, internal role relations, family dominance, child rearing practices, and the physical environment; and
- external functions which incorporate social mobility, social isolation and recreational activities.

Ratings were obtained for family functions with no reference to specific illnesses. A flow model for the study of families and their members may be utilised over a number of days, through the different states of stress, illness and utilisation (Pless et al. 1972). This model appears to require more extensive study and refinement.

2.3.1.4 The Resiliency Model of Family Stress, Adjustment and Adaptation

The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin and McCubbin 1991) emerges as part of the history of theory and systematic research linking physical illness to life stress (Hill 1958, Hill 1949, Holmes and Rahe 1967, Burr 1973, Boyce et al. 1977, McCubbin et al. 1982, McCubbin and McCubbin 1987, Patterson and McCubbin 1983, McCubbin and Patterson 1991).

The model has been based on four assumptions regarding family life:

- Hardships and changes are faced as a natural and predictable aspect of family life over the life cycle.
- Families develop basic strengths and capabilities designed to foster growth and development of the family unit, and to protect it from major disruption.
- Basic strengths and capabilities are developed which protect the family from unexpected or non-normative stressors, and foster their adaptation following a crisis.
- Members benefit from and contribute to the network

of relationships and resources in the community, particularly during periods of family stress and crisis.

This model includes the family's adjustment to cumulative effects of a stressor after the impact of the original crisis, and identifies variables which account for the observed differences among the family's adaptation to stressful situations. While the demand of the chronic illness is the focus of study, the model allows for the consideration of cumulative stressors, for the inclusion of positive events which can be stressors (McCubbin and McCubbin 1991), and for the resources and coping strengths of a family. Family functioning is not viewed as being static, but subject to the resolution of the crisis. The paradigm follows a family systems perspective, where a problem or change in any one member affects other members (Kazak 1989) and the equilibrium of the family system.

The above model offers a conceptual and methodological paradigm (discussed in greater detail in the next chapter) for the assessment of the impact of childhood chronic illness on a family. The model also facilitates psychometric measurement (cf. Chapter 6) of the variables under consideration in the present research, according to its theoretical framework (McCubbin and Patterson 1991, McCubbin and McCubbin 1987). The present study is designed to provide a comprehensive analysis of stress, utilisation of resources and coping process in families of children with asthma, leukaemia and nephrotic syndrome and a control group.

2.3.2 Theoretical Approaches to the Understanding of Family Stress, Coping and Adaptation

2.3.2.1 Conceptualisation of Family Coping

As a result of empirical evidence linking coping to successful individual adjustment, researchers are increasingly of the opinion that the understanding of how families cope with stress is just as important as understanding the frequency and severity of life changes and transitions (Coelho et al. 1974). The importance and interest in family coping has led family stress research away from the view that family stress is dysfunctional, to the view that it is prevalent but not necessarily problematic. Hence the interest in accounting for why some families are better able to endure stress.

In this field, coping has its origins in a cognitive psychological background (Haan 1977) and sociological theory (Mechanic 1974, Pearlin and Schooler 1978), where studies have provided evidence that adults' choices of coping strategies influence the outcome of stressful events (e.g. Menaghan 1982, Pearlin et al. 1981).

2.3.2.1.1 Family Coping Responses

Cognitive coping strategies refer to ways in which a member alters his subjective perceptions of stressful situations. External influences are taken care of through their impact on internal motivation and emotional states. Sociologically, a variety of actions aimed at changing stressful conditions or alleviating distress manipulate the social environment. When

coping is viewed in the context of family demands, it encompasses the effort or behaviour by which a group of members attempt to manage a demand on the family system.

A commonly cited framework which has influenced most of the family coping and adaptation studies is provided by Lazarus (1966, 1976) and Lazarus and Folkman (1984), who regard coping as an important mediator of the impact of minor and major life stresses on the short-term and long-term adaptation of adults, adolescents, and children. Transactions in coping may occur within one specific context, and a number of different coping approaches may be needed to meet the demands of the stressful situation. The function of a particular coping strategy may also be part of the process, that is, it may be either problem-focused or emotion-focused (Lazarus and Folkman 1984). Problem-focused coping refers to problem-solving efforts or actions aimed at reducing stress, while emotion-focused coping refers to the efforts to manage or regulate the emotional states associated with or resulting from the stressor.

Lazarus (1966) also considers stress management to include accepting, tolerating, avoiding or minimising the stressor, cognitively reframing the stressor, or selectively attending to positive aspects of the self or situation, as well as the more traditional view of mastery over the environment. Hence, coping is not restricted to successful efforts, but includes all attempts to manage stress regardless of effectiveness. In this manner, adjustment or adaptation may be facilitated.

While Lazarus's paradigm has been popular in predicting coping within highly defined and situation specific contexts (Krohne 1979, Cohen 1987, Compas 1987), much of the research

has focused on individual coping efforts of adults (Moos 1982, Weisman and Worden 1976, Lambert 1981). This approach has not been considered applicable to the assessment of family coping because of the inability of the paradigm to predict family coping efforts.

Indeed, the family strategy of coping is "...a process of achieving a balance in the family system that facilitates organisation and unity while promoting individual growth and development" (Walsh 1982 p 32). It has been hypothesised that family-orientated coping behaviours will:

- decrease the presence of vulnerability factors, for example emotional instability (Pearlin and Schooler 1978);
- strengthen or maintain family resources (family cohesiveness, organisation, adaptability) which serve to protect the family from disruption (Olson et al. 1985, Olson et al. 1985);
- reduce stressor events; and
- actively influence the environment through a process of change (McCubbin et al. 1976, Pearlin and Schooler 1978).

Family coping is, therefore, considered a dimension of the resources of management. The resiliency model, on which the present study is based, incorporates this view of coping (McCubbin and McCubbin 1991).

2.3.3 Theoretical Approaches to the Understanding of Children's Coping

2.3.3.1 Conceptualisation of Children's Coping

Although the study of coping with stress during adulthood has been characterised by increasing convergence in conceptualisation and measurement (Moos and Bilings 1982, Lazarus and Folkman 1984), this has not been the case with studies of coping in childhood. The literature on chronic childhood illness reveals the absence of an adequate developmental model of coping, and a tendency to rely on models of adult coping (Rutter 1981). Researchers have questioned the "social and ecological" validity of such a background, believing that it may be too "adult-centric" for children (Elwood 1987, Band and Weisz 1988, Dise-Lewis 1988). Indeed, because of the developmental, psychological, physiological and temperamental differences, modifications are required in order to make any adult coping model applicable to children (Kagan 1983, Leiderman 1983, McNabb et al. 1986, Soissignan et al. 1988).

Coping is, therefore, a broadly defined term not used consistently in the literature on children or childhood disease.

2.3.3.2 Children's Coping Responses

From as early as infancy children are confronted with potentially threatening and challenging situations that require adaptation and action. The resources available to cope with stress and the manner in which children actually

cope may be important factors influencing patterns of growth and development (Compas 1987).

In the initial work on the coping processes of children, proponents have placed coping in the middle of a continuum ranging from reflexes that are present from birth to automatised mastery responses that have been learned to the extent that they no longer require conscious control (Murphy 1974, Murphy and Moriaty 1976). The importance of distinguishing coping as including purposeful reactions to stress, to the exclusion of reflexive or automatic responses, has been emphasised (Lazarus and Folkman 1984, Murphy 1974). Coping is also distinguished from instinctual mechanisms that are beyond the individual's control. Purposeful personally-activated responses to stress - that is, cognitive and behavioural strategies - are recognised as mediators of stressful events.

Children are likely to use both problem-focused and emotion-focused coping strategies in dealing with a stressful situation (Lazarus and Folkman 1984). For example, a child who attends the hospital for treatment may attempt to cope by demanding some control over the treatment by insisting that an injection is given to one part of the body rather than another (problem-focused coping). Another child may respond by screaming, yelling, shouting, crying and objecting to the treatment (emotion-focused coping). Although either type of coping can be elicited by any stressor, problem-focused coping is utilised with situations the child views as solvable; emotion-focused strategies may be employed when the child believes that nothing can be done to change the situation, and that the stressor must simply be endured (Folkman and Lazarus 1980). While Lazarus offers a transactional framework for the understanding of coping, his work with children has not reached the same level of

sophistication as that with adults (Carver et al. 1989). It is based on the distinction between two coping processes, an approach which has been found to be too simplistic (Folkman et al. 1985). Similarly, the work of Carver et al. (1989) on 13 scales is still preliminary, and theoretically limited to the understanding of adult coping.

Spirito and his colleagues provide an understanding of how children with chronic illness utilise coping strategies (Spirito et al. 1988, Spirito et al. 1989). It is suggested that there may be differences in the strategies adopted by chronically ill children in dealing with the stressful situation, and in the appraisal of the potential usefulness of the different strategies (Spirito et al. 1988). In following a theoretical formulation (Lazarus and Folkman 1984), a number of cognitive and behavioural coping strategies may be employed in different stress situations by children, namely, a) distraction, b) social withdrawal, c) cognitive restructuring, d) self-criticism, e) blaming others, f) problem-solving, g) emotional expression, h) wishful thinking, i) social support, and j) resignation. The present research attempts to investigate these strategies in children afflicted with asthma, leukaemia, nephrotic syndrome and a control group.

Cognitive coping and strategies aimed at emotional regulation, such as distraction and reframing, have been considered important in facilitating adaptation (Spivack and Shure 1985, Miller and Green 1984). However, controversy exists about the effectiveness of cognitively reframing or avoiding certain aspects of a stressor. The attempts to enhance children's preparation for medical or dental procedures indicate that information about the stressor is beneficial when it is presented in an attenuated form (Miller and Green 1984). In other words, selectively attending to

less threatening aspects of the event, transforming how the event is cognitively processed, and even being distracted from the event itself have been found to benefit children's coping. Utilising cognitive strategies to reframe a stressor may be beneficial when it is beyond the personal control of the child, as is the case with a child suffering from leukaemia and nephrotic syndrome, who experiences repeated medical procedures. This strategy may not be useful when faced with an interpersonal problem over which an individual has considerable control (Forsythe and Compas 1988).

Gender differences in adolescence, as well as age-related differences, have also emerged in relation to the use of coping strategies (Band and Weisz 1988, Compas et al. 1988, Dise-Lewis 1988, Spirito et al. 1988). The skills available to cope with stress may differ significantly as a function of age (Spivack and Shure 1985). By 4 to 5 years of age, children develop the ability to generate alternate solutions to many problems, and this skill remains throughout life. By middle childhood, around 8 to 10 years, other skills emerge, such as the development of "means-end thinking" (mentally identifying the sequence of acts necessary to achieve a particular solution).

The use of one coping strategy over the other varies in effectiveness across different types of stressors (Forsythe and Compas 1988, Spivack and Shure 1982). The use of a particular coping strategy does not imply the presence of an underlying personality trait that predisposes the individual to respond in a particular way, but represents a characteristic response of an individual to stress. There are no universally adaptive responses suitable for everyone in all situations (Eiser 1990). Effective coping is likely to be characterised by flexibility and change. Furthermore, the nature of coping requires that children be adept at

generating a variety of coping strategies for dealing with stressful experiences. A child who has a limited coping repertoire may experience difficulty adapting to the changes and intensity of a stressor such as the chronic disease experience. It has been documented that a greater number of coping strategies reported by children is associated with a lower incidence of behavioural and emotional problems (Robins 1987). Hence, the present research will investigate the repertoire of coping among children with asthma, leukaemia, nephrotic syndrome, and a control group.

Coping is characterised not only by the child's skills or resources alone, but instead lies in the relation between the child and his environment (Rutter 1981, Kagan 1983). Cognisance is taken of the fact that child behaviour is the product of a multi-causal system (for example, a parent can influence the adoption of a particular coping strategy by a child) (McNabb et al. 1986). Basic features of cognitive and social development may also affect what children experience as stressful and how they cope (Maccoby and Martin 1983). Self-perception (Harter 1983) and self-efficacy beliefs (Bandura 1981), amongst others, are important. Therefore, parent and family coping processes are considered contextual variables in the assessment of coping and the development of self-esteem in the child.

With this theoretical background, the study will explore the value of coping strategies in relation to specific diseases, and attempt to determine to what extent coping strategies characterise specific illnesses.

2.3.4 A Theoretical Understanding of Self-Esteem as it relates to Chronic Illness

The literature on self-esteem reveals vast and disparate information in terms of its theoretical constructs, data bases and research paradigms (Brissett 1972). In the context of the present research, the following literature review focuses on self-esteem as it relates to chronic illness.

The most appropriate definition of self-esteem for the study of adaptation to chronic illness has been proposed by Cotton (1983). The schema of a developmental line of self-esteem has its origins in the developmental lines model of self development in childhood (Freud 1965). This model is interdisciplinary and complementary to a biopsychosocial approach. It also recognises the multi-dimensional aspects of self-esteem which differentially influence the origin and sustenance of self-esteem according to age (Cotton 1983). Physical illness has distinct implications at each stage of self-esteem development and has the potential to increase the difficulty of or prevent the progression from one stage to the next (Perrin and Gerrity 1974). Such phase progression facilitates identification of those elements of self-esteem development in the chronically ill middle-aged child, with which this research is concerned. A definition of self-esteem which lends itself to be operationalised for measurement is a "multi-dimensional schema" (Cotton 1983 p 22). The major components of self-esteem are referred to as competence or mastery (Freud 1952, Harter 1982), self-confidence (Rosenberg 1979), esteem by others (Winnicott 1965), and the capacity for self-evaluation (Brissett 1972). These initially separate influences become increasingly intertwined in the course of development. By school age they are indistinguishable.

2.3.4.1 Components of Self-Esteem

The major components of self-esteem are, namely:

- competence or mastery;
- esteem by others or self-worth; and
- self-evaluation.

These components are described below:

1. An important component of self-esteem is competence or mastery (Freud 1952) or self-confidence (Rosenberg 1979). In the early 1950's, Anna Freud espoused the sense of control over one's environment and one's own body as a developmental task in infancy. Essential to the development of self-esteem is the ability to control one's impulses and then to utilise them constructively in building, planning and learning (Freud 1965). This sense of mastery is crucial to a child's development as the child moves towards a "growing competence to deal with things by his own efforts" (White 1965 p 113). Self-esteem has frequently been equated with self-confidence. However, self-confidence is one component of self-esteem, and is linked to "mastery" (Rosenberg 1979). Self-confidence is defined as an "anticipation of successful mastery of challenges or obstacles" and an "inner belief that one can make things happen" (Rosenberg 1979 p 31). Such a distinction has been well supported by research. For instance, in a study of racial issues, Rosenberg (1979) identified slightly lower levels of self-confidence in children (but equal levels of self-esteem) due to societal stigma and

oppression. In other words, societal prejudice and oppression may reduce a child's inner belief and sense of mastery. It was also noted that while boys and girls had approximately the same self-esteem scores, girls were found to have lower self-confidence (or sense of mastery scores) (Maccoby and Jacklin 1974). Thus, self-confidence (not self-esteem) varies according to socio-culturally defined opportunities for mastery. For instance, the attribution pattern of helplessness in children are found to occur more often in girls than boys and has been linked to the socialisation processes in a classroom (Dweck et al. 1980). This distinction is highly significant for children with chronic illness where certain societally defined mastery skills are limited because of the illness.

2. The second component of self-esteem is "esteem by others," or self-worth, and is further divided into two sub-components:

i) development of a sense of "basic acceptance" (Norem-Hebeisen 1976), which is based on internalisation of the child's social or interactive environment (Winnicott 1965); and

ii) development and internalisation of "ideal" and "real" images of the self (Kohut 1972, Mahler et al. 1975). The value judgements of others are considered extremely important (Rosenberg 1979).

Parental "atmosphere" or quality of interaction with the child is a force that will promote and facilitate the natural tendencies in a child's

life toward growth and maturation (Winnicott 1965). "When conditions are not good enough these forces are contained within the child, and in one way or another tend to destroy the child" (Winnicott 1965 p 65). Therefore, the manner in which a family handles a child's hurt, emotional pain and developmental crisis (Erikson 1968) will either enhance or impede that sense of being valued - that is, internalised esteem (Mack 1983).

The other sub-component of "esteem by others" is development of an internalised, idealised self-image and a real self-image (e.g. Kohut 1972). High self-esteem correlates with the ability to match the ideal self with one's real capabilities, so as to be satisfied with who one is, capable of acknowledging one's faults, as well as appreciating one's merits (Rosenberg 1979). Blanck and Blanck (1974) have attempted to integrate self-confidence and real-ideal image congruity by defining good self-esteem as the favourable self-image which results from internalisation of parental affection combined with favourable experiences of success in mastery, where the "ideal" is internalised parental affection and the "real" is the experienced success in actual mastery. The development of these inner images is based not only on parental values and attitudes in infancy but on all significant people in the child's environment. A child who is unable to construct internal images of himself, or has constructed images which are destroyed by reality testing is deprived of an available source of self-esteem (Kohut 1972, Dare and Holden 1981, Harrison 1983). This view has important implications for a chronically ill child who may be deprived of mastery of a certain developmental task as a consequence of the limitations of the illness, affecting the real/ideal congruence of his self-image

(Harrison 1983).

3. The third component of self-esteem is the capacity for "self-evaluation." Building on the development of a sense of competency and of being esteemed by others, a cognitive-affective process of self-evaluation develops. This development continues throughout life and fluctuates continuously according to maturational and environmental contingencies. The process of self-evaluation is unique for each individual. This may be understood in terms of the concept of "psychological centrality" (Rosenberg 1979 p 84). Not all significant others are equally significant in the development of one's self-concept. Whether or not the other person's opinion is valued and respected by the child will determine the "psychological centrality" for that child. This capacity for selective significance develops in the pre-school child and is well established by school age. The concept refers to self-attributes: how much a person values an attribute affects the self-evaluation according to that attribute. As such, centrality allows for regulation of high levels of self-esteem in the face of criticism or specific failure. This process would undoubtedly be significant in a child who suffers from a serious illness.

2.3.4.2

Self-Esteem and Developmental Age

The regulation of self-esteem occurs throughout life and requires an ability to organise, select, assign value to and synthesise information from the various sources of self-esteem. By school age or latency the three sources of self-esteem are well integrated in normal development. By this

time a strong self-structure has usually developed; one which is impervious to minor slights, or one which is negative and is incapable of feeling good (Cotton 1983).

As this is also a period of skill building, school success and industry will enhance self-esteem. However, self-esteem regulation is especially sensitive to rejection, failure and to physical defects. This is not surprising, as children of this age tend to focus on the most visible aspects of themselves (Rosenberg 1979). Thus, while the period of self-formation (infancy and the first years of life) is sensitive for positive self-esteem (Cotton 1983), self-esteem in later stages is open to repeated re-negotiation.

The middle school age, which is the sample selected for this study, with its emerging sense of independence, achievements, physical characteristics, focus on ability, and repertoire of defense mechanisms, is a sensitive stage during which failure or success of self-esteem maintenance and development will have critical consequences in coping and adaptation.

2.3.4.3 Chronic Childhood Illness and Self-Esteem

The present study focuses on chronic childhood illness and coping and self-esteem development in the middle school-aged child, between eight and twelve years.

Studies on children have documented the effects of physical illness or defects on psychosocial development at earlier ages (Freud 1952). While these studies do not warrant discussion here, it is necessary to acknowledge their

significance in that congenital illness or defects may cause emotional trauma to the developing self which could affect later regulation of self-esteem. Early physical defect is likely to cause distortion in development of the body-image of the child (Harrison 1983). If it remains an area of unresolved conflict through ongoing interference with mastery of developmental tasks (Freud 1952, Harrison 1983), the child may develop an early sense of failure.

The mastery of early bodily functions and related skills is viewed as a foundation in reality for self-esteem development (Coopersmith 1967, Cotton 1983). As parent-child relationships are essential to a sound and healthy esteem development (Winnicott 1965), bodily defects within the first years of life may also have a bearing on the relationship. Lack of sufficient mirroring may result in the child's inability to form a healthy self-image or trust in the self (Kohut 1972, Erikson 1968), making it difficult later to enjoy or feel pleasure in "being" oneself. It is necessary to note, however, that while a chronically ill child may have suffered severe frustrations of early mirroring, it is possible for the child to find significant others as self-objects later in life (Ornstein 1978), thus compensating for and correcting the early defect.

Regardless of age of onset of the chronic disease, a child approaching latency will always be vulnerable to a sense of "differentness." The need for approval and acceptance by peers is crucial (Hurtig and White 1986, La Greca 1990). In other words, the significance of the esteem of others or "perceived self" is present at this stage. Failure is traumatic at this age, particularly if the child is not able to keep up with peers. Negotiation of such a crisis will lead to either a healthy or impaired self-esteem regulation based on sensitivity to involvement of significant others in

the child's life. The consequences of successful intervention by psychologists for chronically ill children at this age could make the difference between a psychologically healthy, happy life and failure and anxiety. Perrin and Gerrity (1984) state that chronically ill children are at risk of becoming underachievers and failures in their own eyes and the eyes of peers. They miss out on the experiences leading to normal development of self-esteem and the sense of mastery and control over their environment that is so critical for normal development at this age. Thus, the creation of an environment which facilitates development or refinement of ideal self-images by identifying and matching an ill child's actual capabilities will enhance self-esteem.

Adaptation to chronic illness will involve the tasks reflected by the components of self-esteem, which involves the assessment and "integration" of new experiences. Coping with illness then, requires a re-negotiation of the tasks of the child's self-esteem with each new illness experience (Drotar 1981). Emotional sequelae may arise because of the altered biopsychosocial situations which the chronically ill child experiences (for example, hospitalisation, the conceptualisation of the illness, feeling "different", social and physical restrictions, and assimilation of family responses (Barbarin 1990, Friedman and Mulhern 1992). How these experiences are integrated into the developing personality and self-concept is a major factor in determining the choice of coping strategy and ultimately the quality of adaptation.

With this theoretical background, the present investigation is designed to assess the self-esteem of a control group and children who have been diagnosed with asthma, leukaemia and nephrotic syndrome. The study will also attempt to determine whether a relationship exists between children's self-esteem

and their coping strategies.

The following chapter examines the resiliency model of family stress, adjustment and adaptation in detail.

CHAPTER THREE

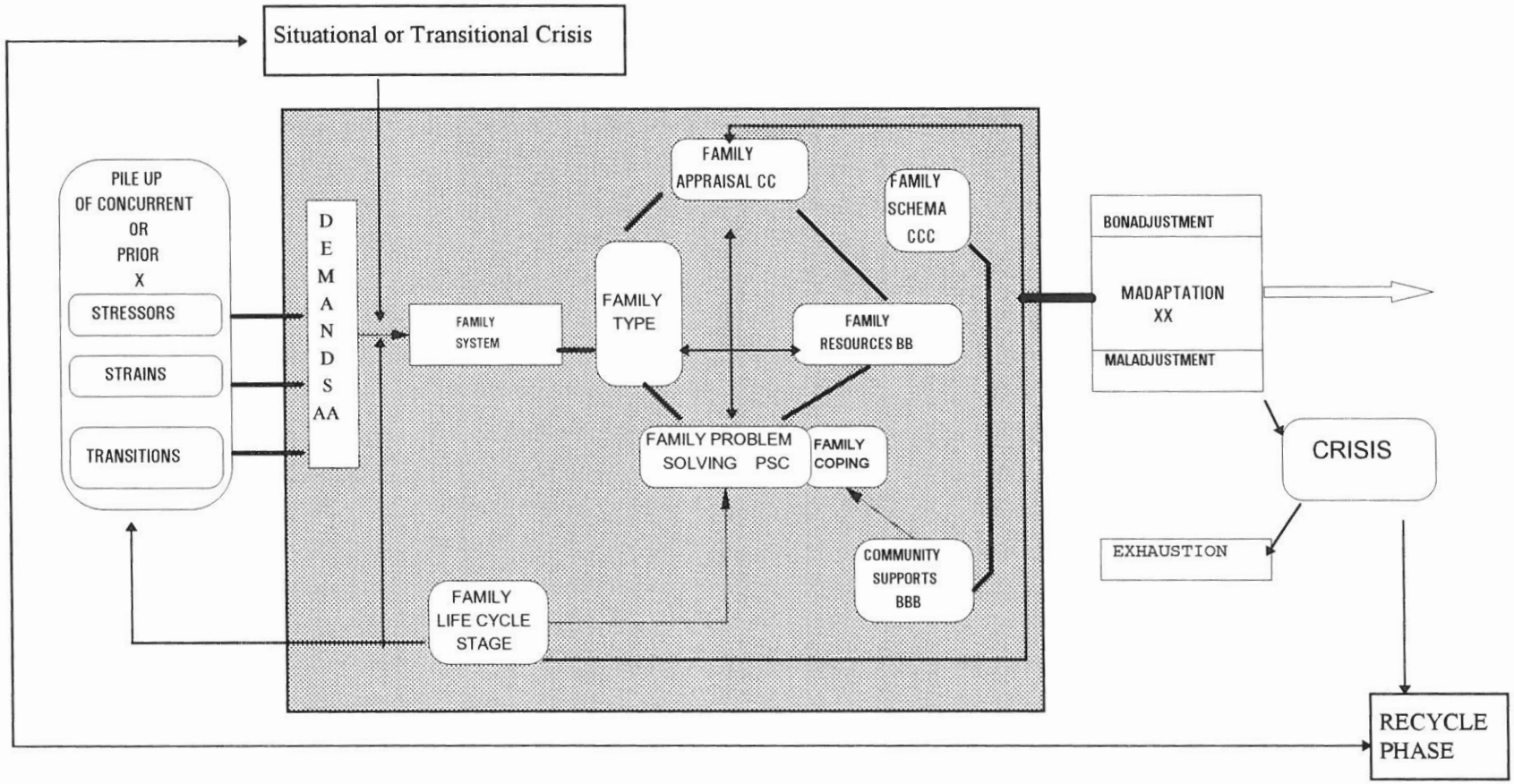
ANALYSIS OF THE RESILIENCY MODEL OF FAMILY STRESS, ADJUSTMENT AND ADAPTATION

As the resiliency model has been selected for the present study, an analysis of this paradigm is necessary.

The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin and McCubbin 1967, 1987) focuses on the level of family adaptation (XX) and/or the family's transition back into a crisis situation (or exhaustion) in response to a stressor which is determined by the pile-up of demands on the system, life cycle changes and unresolved strains (AA). This is mediated by the family's efforts or capacity for meeting the demands (adaptive strengths, capabilities, resources)(BB), and by the appraisal of the situation (CC), schema (CCC), social support (BBB), problem-solving and coping responses (PSC), in an attempt to achieve a balance in family functioning and adaptation. Figure 1 graphically illustrates the family adaptation phase of the resiliency model.

Figure 1 FAMILY ADAPTATION PHASE OF THE RESILIENCY MODEL

(McCubbin and Patterson 1991)



3.1 The Family Adaptation Phase

The present research focuses on the adaptation phase. There are two phases to the model: adjustment and adaptation, which are separated by a period of crisis during which the family homeostasis is upset. Family adaptation is a central concept in the adaptation phase, focusing on the efforts over time of the family to recover from a crisis situation. It differs from adjustment, which is a short-term response by the family to manage life changes, transitions and demands (McCubbin and McCubbin 1991).

The value of the above conceptualisation is that it attempts to guide research to the type of family strengths and capabilities that are needed, called upon or created to manage a major transition (such as chronic childhood illness) or change calling for family reorganisation and adaptation.

3.1.1 Components of the Resiliency Model

The adaptation phase of the resiliency model is an attempt to describe:

- the additional life stressors and changes which influence the member's ability to achieve adaptation;
- the critical psychological, family, and social factors members rely upon and utilise in adaptation;
- the process engaged in order to achieve satisfactory adaptation; and
  the outcome of these family efforts (McCubbin and

McCubbin 1991).

The above mentioned factors are considered important in the present study on the assessment of the stressors, resources and coping processes of families to the illnesses of asthma, leukaemia and nephrotic syndrome.

3.1.1.1 Adaptation (XX Factor)

There is a demand-capability imbalance when stress or distress occurs. A adaptation or outcome of family efforts is to achieve a new level of "balance and fit" after the crisis. This refers to the ability of the family to change in response to external stressors and stimuli (Kazak 1988) through reciprocal relationships at two levels of functioning, viz., the individual to family level, and family to community levels. At the second level, this occurs with the family unit and the work community competing for the involvement and commitment of family members, often resulting in stress (McCubbin and McCubbin 1991).

3.1.1.2 Demands Pile - Up (AA Factor)

Families with chronic illness experience a pile-up of demands as crises evolve and are resolved (McCubbin and McCubbin 1991). They are exposed to more than one stressor. The demands of individual and community members change over the period of the illness. Worry, fatigue and isolation are examples of pile-up which can occur with a single stressor. In childhood cancer, for example, remission may also engender distress, and families experience other concurrent stresses unrelated to the illness (Kalnins et al. 1980, Kazak 1989).

Additional sources of demands on the family may be life event stressors such as a birth of a baby, the normative growth and development of individual members in the family, and so on.

There are five kinds of stressors:

- initial stressor/crisis and its hardships: With the occurrence of a crisis situation, changes in practice emerge in an attempt to adapt to the stressful situation, possibly resulting in hardships which might intensify the difficulties.
- normative transitions: These include normative growth and development of the child (such as an increasing need for supervision) and adult members (for example, spouses desiring to continue with their career), and changes in society. These are independent of the initial stressor or crisis, but occur at the same time.
- prior strains: Inherent in the system are residue strains, which may be the result of unresolved hardships from earlier stressors/transitions in parent or employer roles (Pearlin and Schooler 1978). In the event of a new stressor, prior strains are exacerbated and contribute to the pile-up of difficulties.
- consequences of family efforts to cope: These include specific behaviours which are adopted in an effort to cope with the crisis situation, for example, the consumption of alcohol.
- intra-family and social ambiguity: Since change and the demand for adaptation produces uncertainty, ambiguity is inherent in every crisis situation. The family may also experience ambiguity about its structure, roles, rules, responsibility, and durability, particularly in the case of a chronic disease (McCubbin and McCubbin 1991).

The family's ability to manage stress may further be influenced by the solutions its community provides (such as social policies and programmes), which may reduce the strain of ambiguity (McCubbin and Patterson 1982). In the absence of the expectation that society offers guidelines for families coping with crisis, it is probable that families will face the added strain of social ambiguity, and family adaptation will then be unclear and absent.

3.1.1.3 Family Strengths, Resources and Capabilities (BB Factor)

Capabilities are defined as the potential the family has available to meet its demands. Resources and strengths refer to what the family has, and coping behaviour is what the family would do. An adaptive resource is a competency of one of the two systems.

A number of potential resources have been identified. These are:

- personal resources include innate intelligence that enhances awareness and comprehension of demands and facilitates mastery;
- knowledge and skills acquired through education, experience, etc., in order to perform tasks necessary for daily living;
- personality traits (such as a sense of humour) which may facilitate more efficacious coping behaviour;
- physical and emotional health so that intact

faculties and energy may be available for meeting the demands;

- a sense of mastery (belief that one has control over the circumstances of ones's life); and
- self-esteem.

The latter two resources are believed to be critical in the stress process and in managing crisis (McCubbin and McCubbin 1991). At the same time, they are readily threatened when the pile-up of demands increases, particularly with chronic strains or illness, implying a failure at mastery. Finally, time is an important factor since its allocation and utilization is important in the management of demands.

3.1.1.4 Family System Resources

The following resources have been documented:

- cohesion (the bonds of unity in family life) and adaptability (the family's capacity to meet its demands and make the necessary changes) (Olson et al. 1985);
- family organisation, which includes agreement, clarity and consistency in family role and structure (Moos 1974, Moos 1976). Additional resources are shared parenting and clear generational boundaries (Lewis and Looney 1984); and
- communication resource (Spinetta and Deasy-Spinetta 1981, Epstein et al. 1982).

The process of managing family resources in stress situations has emerged as an important aspect of family behaviour under

stress. Ideally, resources should be allocated among multiple goals to meet the needs of the family and to satisfy relationships (Paolucci et al. 1977). The family may be seen as a resource exchange network in facilitating adaptation to chronic childhood illness.

3.1.1.5 Community Resources and Support (BBB Factor)

At a micro level, community-based resources may include health-care services, the school, the church, employers, and so on, which the family may utilise to meet their demands. At a macro level, government and judicial policies have been included (McCubbin and McCubbin 1991).

Social support is one of the primary buffers or mediators between stress and illness (Cohen and Wills 1985, Thoits 1986), thereby contributing to a family's adaptation. It has also been emphasised as promoting recovery from stress or crisis, thus contributing to the family's regenerative power.

The resiliency model has expanded on this definition (which included emotional support, esteem support and network support), to include appraisal support and altruistic support. Appraisal support refers to feedback assessing how well the individual is performing with life tasks. Altruistic support reflects the good/charity received or carried out/given. It is important to differentiate social support from social network, the latter being contact people who form a potential source of support. Network members may not always provide support; they may be a source of demand (McCubbin and McCubbin 1991). Social support may also be information disseminated with regard to problem-solving and new social contacts for help (House 1981).

Social support makes individuals and family systems less vulnerable to stressors such as illnesses like asthma (de Araujo et al. 1973) or leukaemia (Kaplan et al. 1973) and has also been found to be particularly important for parental coping (Unger and Powell 1980, Kazak and Wilcox 1984, Kazak 1988).

3.1.1.6 Appraisal

There are three types of appraisal:

- Family appraisal refers to the family's appraisal of the specific stressor or strain.

- Situational appraisal refers to the perceptions the family has and responses the family makes to the demands of the stressful situation. This may be influenced by the experience of a prior strain. The problem might also be perceived differently as a result of new learning and experiences which will facilitate coping.

- Global appraisal and family schema (CC Factor). Schema refers to the set of beliefs members have about themselves in relation to other members, and about their family in relation to the wider community. According to McCubbin and McCubbin (1991), schema are perceived as having five dimensions, namely,
  i) shared purpose;
  ii) shared control;
  iii) frameability;
  iv) collectivity; and

v) relativism.
This component is influenced and shaped over time in response to the stressful illness experience. It is more stable than situational appraisal, which is subject to influence.

Although appraisal may be held individually, it is shaped and shared by the family. This process of developing a meaning of the experience is an important part of the stress process (McCubbin and McCubbin 1991). Thus, the manner in which a family perceives chronic illness is related to their adaptation.

3.1.1.7 Adaptive Coping

The resiliency model views the process of acquiring and allocating resources as critical. The family is viewed as a resource exchange network, and coping is perceived as the action for this exchange. Adaptive coping includes:

- coping behaviour, which is a "specific effort" by which an individual or family attempts to manage or reduce a demand experienced by the system. Its function is to maintain and restore the balance between demands and resources;
- family coping, which is not only the "co-ordinated problem-solving behaviour of the whole system," but may be viewed as "complementary efforts" of individual members which "fit together as a synthetic whole" (Klein and Hill 1979 p 22);
- coping patterns (specific behaviours grouped together) are generalised responses that transcend

different situations. For example, in the context of a pile-up of multiple demands, coping is viewed as a generalised response.

A balance may be achieved between the demands that are experienced and the resources in the following ways:

- Coping may involve direct action to reduce the number and/or intensity of demands (for example, home treatments, such as the aerosol for an asthmatic child).
- Coping may entail direct action to acquire additional resources (such as seeking appropriate medical assistance and diagnosis for a chronically ill child).
- Coping involves maintaining existing resources which are allocated or reallocated to meet changing demands (for example, maintaining extended support ties for emotional support).
- Coping may also entail responding to ongoing strains and tensions (by exercising, utilisation of humour), and so on.
- Coping may require reframing of a situation to make it more tolerable or manageable (for example, by focusing on spiritual beliefs to build hope) (McCubbin et al. 1983, McCubbin and McCubbin 1991).

3.1.1.8 System Strategies of Adaptive Coping

The support and resources available to the family assist by buffering the impact of the demands, and by influencing the appraisal of the stressful situation and maximising the solutions available.

The family's adaptive coping strategies for chronic childhood illness include synergising (family efforts at mutuality and interdependence), interfacing (with community and social institutions) and compromising (a realistic definition of the circumstances and acceptance of less than perfect resolutions) thereby allowing for successful adaptation (McCubbin and McCubbin 1991).

3.2 The Resiliency Model as it Applies to Health Care

The assumptions underlying the resiliency model are applicable to the present investigation because of its family-oriented medico-psychological approach.

- The relationship between family functioning and the health status of family members can be examined through the systematic assessment of the demands placed on the family system by the illnesses of asthma, leukaemia and nephrotic syndrome, and the resources and coping behaviours used to manage these demands.
- The demands of the family unit, if not mediated or buffered by resources and coping, will increase the probability of emotional and/or health problems.
- Additional or concurrent family demands, which are not mediated by the family's resources or coping, will complicate medical treatment and the long-term rehabilitation or recovery of the ill child.
- *The assessment of demands (stressors), resources, and coping may guide the clinician's interventions and supportive interactions. It may in turn shape the family's response and ultimately the family environment, to be more appreciative of family life*

and of medical and clinical interventions.

The resiliency model represents a generic model to accommodate the stress of chronic childhood illness, and other stresses which may be experienced. It allows for the appreciation of the complex sequence and interaction of the various processes, such as the management of resources and the understanding of the coping processes utilised in the accommodation of chronic illness. As indicated in the previous chapter, this deductive theoretical model follows a family system perspective and has further attempted to facilitate the measurement of family stress, resources and coping, with which this research is concerned.

The next chapter will focus on the presentation of instruments of measure to be used in this investigation.

CHAPTER FOUR

THE INVESTIGATION

This chapter details the hypotheses, sample selection, instruments and methodology used in the study.

4.1 Hypotheses

Based on the literature reviewed in the previous chapters, the following hypotheses and sub-hypotheses have been generated:

- There will be significant differences in family life events and changes across the four groups of families.
  - a) There will be significantly more family life events and changes in the asthma, leukaemic and nephrotic syndrome groups than in the control group.
- There will be significant differences in the stress profiles of the four groups of families.
  - a) The illness groups (viz. asthma, leukaemia and nephrotic syndrome) will experience significantly more stress than the control group.
- There will be significant differences in the utilisation of resources by the asthmatic, leukaemic, nephrotic syndrome and control groups.
  - a) The illness groups will utilise significantly more resources than the control group.

- There will be significant differences in the health-related coping patterns of the four groups.
    a) The illness groups will utilise significantly more patterns of health-related coping than those in the control group.
- There will be significant differences in family crisis-oriented coping strategies among the four groups.
    a) Each of the illness groups will utilise significantly more coping strategies than the control group.
- The chronically ill group (that is, the three illness groups combined) will experience more family life events and changes than the control group.
- The chronically ill group will experience more stress than the control group.
- The chronically ill group will manage their resources differently from the control group.
- The chronically ill group will utilise significantly more health-related coping patterns than the control group.
- The chronically ill group will utilise significantly more family crisis oriented coping strategies than the control group.
- The induction phase sub-group will experience significantly more stress than the remission sub-group.
- The induction phase sub-group will utilise significantly more resources than the remission sub-group.
- The induction phase sub-group will utilise significantly more health-related and crisis-oriented coping patterns than the remission sub-group.
- There will be significant differences in the stress experienced by families of boys and girls.
- Family utilisation of resources and coping patterns will differ in respect of the gender of the child.

- There will be significant associations between certain coping strategies and resources, and certain stressors.
- There will be significant differences in the coping strategies used by children in the asthma, leukaemia and nephrotic syndrome and the control groups.
- There will be significant differences in the coping strategies of chronically ill and control children.
    a) The chronically ill group will utilise significantly more coping strategies than the control group of non chronically ill children.
- There will be significant differences in the coping strategies used by children in the induction and remission sub-groups.
- There will be significant differences in the coping strategies used by boys and girls.
    a) Girls will utilise more coping strategies than boys.
- There will be significant associations between children's coping strategies and health-related and family coping patterns and resources.
- There will be significant differences in the self-esteem of the children in the asthma, leukaemia and nephrotic syndrome and control groups.
- Chronically ill children will display significantly lower self-esteem than the control group of non chronically ill children.
- Children in the remission sub-group will have a significantly higher self-esteem than those in the induction sub-group.
- There will be significant differences in the self-esteem of girls and boys.
- There will be significant associations between children's self-esteem and coping strategies.
- There will be significant associations between children's self-esteem and self-worth.
- There will be significant associations between

children's self-esteem and family resources and coping patterns.

4.2 Methodology

The investigation entails the analyses of questionnaire responses obtained from

- children who experience chronic illnesses,
- mothers of children who are chronically ill,
- a control group comprising non-chronically ill children, and
- a control group of mothers of non- chronically ill children.

Table 1 : Distribution of four groups comprising total sample

Group	Children N	Mothers N	Total
Asthma	30	30	60
Leukaemia	23	23	46
Nephrotic Syndrome	22	22	44
Control Group	30	30	60
Total	105	105	210

4.3 Sample Selection

The children in the chronic disease samples were drawn from three diagnostic groups: asthma, leukaemia and nephrotic syndrome. The children in the control group were selected from a paediatric population who presented with minor physical complaints such as, the common cold, influenza or minor dental problems. They had no chronic illnesses. The rationale for selecting mildly ill rather than healthy children as control subjects was to eliminate disease or illness as an explanation for any differences that might be obtained. The control group was further matched for group mean age and cultural homogeneity.

Mothers were chosen as primary respondents to complete the family questionnaires. The reason for this selection have been delineated in Chapter One). While the examination of both parents of a chronically ill child would seem to be an important part of data collection, it was difficult for many reasons. Fathers were often unavailable because of the practical demands of their work. The present economic climate necessitated working, in many cases, throughout the week (6 days). The threat of retrenchment also made it difficult for them to take time off from work.

The criteria adopted in the selection of patients were:

- age of children : middle-childhood (8 to 12 years)
- cultural group : Indian.

4.3.1 Children's Ages

Table 2 displays the mean ages of the four groups of children.

Table 2 : Mean ages of the four groups of children

Group	N	Mean Years	SD
Control	30	9.5	0.1357
Asthma	30	9.5	0.1306
Leukaemia	23	9.1	0.1402
Nephrotic	22	9.7	0.1315

Children in the total sample had a mean age of 9 years 4 months, thus fulfilling the inclusion criteria.

Both the leukaemic and nephrotic syndrome samples had passed the diagnosis and acute phases of their illness. They were either in the phase of induction or remission. As asthma does not follow such distinct stages, children who were receiving regular treatment (medication, bronchodialators) were included in the study. Thus, all of the children in the chronic illness sample were receiving on-going treatment.

Given the limited accessibility of the conditions under study, the inclusion criteria were kept to a minimum. The sample of leukaemia and nephrotic subjects was restricted by the rarity of conditions. Nephrotic syndrome, particularly, is represented by small numbers throughout the world (Adhikari, personal communication).

The asthmatic sample and the control group of paediatric patients were drawn from R.K. Khan hospital in Chatsworth. The leukaemia and nephrotic patients were obtained from the Paediatric Haematology and Oncology, and Renal clinics at King Edward VIII Hospital, which services the needs of such children from Durban and outlying areas.

4.4 Illness Sub-groups

The samples of leukaemia and nephrotic syndrome were further divided into the remission and induction sub-groups. (See Table 3.)

Table 3 : Illness sub-group

	Sub-group	
	Remission	Induction
	N	N
Leukaemia	11	12
Nephrotic	11	11
Total	23	22

4.5 The Instruments

The following instruments were used in this study:

- Family Inventory of Life Events and Changes (FILE)

- Family Inventory of Resources for Management (FIRM)
- Coping Health Inventory for Parents (CHIP)
- Family Crisis Oriented Personal Evaluation Scale (F-COPES)
- Questionnaire on Resources and Stress (QRS)
- Kidcope
- Self-Perception Profile for Children

All seven measures (including a biographical questionnaire) were administered to the clinical and control groups.

The seven instruments used in this investigation have been developed and empirically validated in the United States. The lack of standardised South African measuring instruments made it necessary to use these clinical measures. At present, many empirical studies conducted in South Africa rely on overseas measures. However, with adequate control these measures can be used with satisfactory results.

Consent for use of the tests was obtained from the authors of the measures. The researcher has also been in direct consultation with Anthony Spirito regarding the coping investigation and with Susan Harter regarding her scale of self-perception. However, because of the copyright on the QRS, the FILE, FIRM, CHIP, F-COPES and the Self-Perception Profile for Children, it has not been possible to reproduce these tests in this dissertation.

4.6 Description of Measuring Instruments

4.6.1 Biographical Questionnaire

A biographical questionnaire or family information form (See Appendix A) developed by the researcher, was administered to mothers and children to record salient personal and demographic details of the family. Demographics were collected during a general information interview with the mother and then with the child; when possible, the father and siblings were also present. Information about parental level of education, employment status, income and other relevant data was collected. The interview questionnaire also included information about the severity of the child's symptoms and prognosis (parental rating), satisfaction with medical information received, and so on. The second part of the inventory contained the child information form designed to obtain information relating to the child, such as age, sex, age of onset of illness, number of admissions to hospital, and so on.

Contextual information was gained through a context-specific interview incorporated into the biographical inventory. The questions tapped cultural and familial beliefs and practices in relation to having an ill person at home. The questions were designed with a view to obtaining a deeper understanding of a variety of contextual factors and their influences on the family's perceptions of the illness and their adaptation to it.

4.6.2 The Resiliency Measures of Family Stress, Adjustment and Adaptation

The use of family assessment measures in health care research and practice is based on the premise that family functioning interacts with individual physiological and psychological processes in a discernable and predictable manner (McCubbin and McCubbin 1991). This consequently affects the health status of family members and has important implications for family oriented medical and psychological interventions.

Developed at the Family Stress Coping and Health Project in Wisconsin, USA, the battery of resiliency measures is currently used in health-care and family-oriented investigations (McCubbin and Thompson 1991). They have been primarily designed to assess the critical dimensions of the resiliency model, namely the stress experienced, resources utilised, coping patterns and appraisal of families who have a child with chronic illness.

The following resiliency measures were used in the present research:

- Family Inventory of Life Events and Changes (FILE);
- Family Inventory of Resources for Management (FIRM);
- Coping Health Inventory for Parents (CHIP); and
- Family-Crisis Oriented Personal Evaluation Scale (F-COPES).

4.6.2.1 The Family Inventory of Life Events and Changes (FILE)

4.6.2.1.1 Introduction

Considerable attention has been focused on the concept of stress resulting from the accumulation of life events as being influential in the aetiology of somatic and psychiatric conditions. However, the concept of "cumulative life changes" has not been applied to the study of family behaviour in response to stress. Most life stress investigations focus on the individual and his or her adaptive reaction to social stressors, with only a few events pertaining to family life. McCubbin and Patterson (1991 p 81) note that "This systematic method of inquiry has not been applied to the family in an effort to quantitatively document the impact of family life events and changes on the family system and individual members."

As early as 1929, Cannon showed that stimuli associated with emotional arousal, such as life events, cause changes in physiological processes. In examining the relationship between ordinary life events and illness, it is noted that the human body attempts to maintain homeostasis. Any life change which upsets the body's state necessitates an adjustment. Excessive changes tax the body's capacity for adaptation, thereby producing stress. Consequently life events are conceived of as "stressors" which require change in the individual's life pattern (Holmes and Rahe 1967). Stress, therefore, is the organism's physiological and psychological response to the stressor. This occurs particularly when there is a perceived imbalance between environmental demands and life changes, and the individual's capacity to meet these demands. It is expected that a pile-

up of life changes will be associated with a decline in family functioning and with negative correlates in individual members (McCubbin and Patterson 1982).

4.6.2.1.2 Description

Developed by McCubbin et al. (1979), FILE is a 71-item instrument designed to measure the pile-up of stress by recording normative and non-normative life events and changes experienced by a family during the twelve months prior to the interview. According to family stress theory, events affecting any one person in a family affect others to some degree. Therefore, a change anywhere in the system requires readjustment by the whole system. Life events are added together to determine "magnitude" of life changes. The concept of "pile-up" of family life changes offered by McCubbin and Patterson (1982) refers to cumulative life changes that may tax the family to adjust to them. This may be associated with a decline in family functioning and negative consequences in individual family members. More specifically, stress may contribute to the onset of a disease. However, a medical condition and its treatment may also render the family vulnerable or incapable of responding in a constructive manner to the needs of the member who may be chronically ill. Thus, FILE provides an index of family stress at a single point in time. When viewed simultaneously with a family's resources and/or coping repertoire, an assessment of family vulnerability can be made.

4.6.2.1.3 Conceptual Organisation

FILE is conceptualised into nine scales, namely,

- Intra-family strains (Intrstr):
  This scale comprises seventeen items which pertain to two dimensions:
  a) conflict (between family members); and
  b) parenting strains.

- Marital strains (MaritStr):
  There are four items in this scale measuring stressors arising from sexual or separation issues.

- Pregnancy and childbearing strains (PregStr):
  This scale has four items which reflect pregnancy difficulties or the addition of a new member to the family.

- Financial and business strains (FinStr):
  This twelve-item scale comprises two dimensions, namely:
  a) family business, reflecting strain arising from family-owned business or investment; and
  b) family finances, which assesses sources of increased strain on a family's income.

- Work-family transitions and strains (WorkFam):
  There are ten items in this scale which comprises two dimensions:
  a) work transitions related to moving in and out of the work force; and
  b) family transitions and work strains which focus on changes in work or moves made by any one family member.

- Illness and family "care" strains (IllFam):
  This eight-item scale has three dimensions:
  a) illness onset and child care which reflect

dependency needs arising from injury or illness of family member or problems with child care;

b) chronic illness strains which relate to the onset of or increased difficulty with chronic illness;

c) dependency strains refer to the strain of a member or relative requiring more help or care.

- Losses:
  The six items in this scale reflect losses due to death of a close person or broken relationships.

- Transitions "in and out" (Trans):
  This scale has five items which reflect a member's moving out or moving back home, or beginning a major involvement outside the family.

- Legal (LegVio):
  The five items in this scale focus on a member transgressing societal laws.

4.6.2.1.4 Administration and Scoring

FILE may be administered to one or both parents in the family unit. The respondent is asked to record a "yes" or "no" to the life events and strains that happened to any member of the family unit and to the family as a group during the past year. FILE is a brief instrument requiring approximately 10 minutes completion time.

FILE may be scored in five different ways depending on the use of the statistical information (McCubbin and Patterson 1983c). FILE yields both total scores and weighted scores; it can also be scored to yield specific realms of strain (for

example, financial strain, illness strain). For the purpose of this research, scoring was computed by giving each of the "yes" responses a score of 1 and each of the "no" responses a score of 0. The "yes" responses are added to arrive at a score for each of the subscales and the total pile-up scale. A higher score implies higher stress.

Separate norms are available for husbands, wives and couples (McCubbin and Patterson 1991).

4.6.2.1.5 Reliability

In the original development phase, FILE was administered to a sample of 322 families who had a chronically ill child (cerebral palsy and myelomeningocele). Data from this sample was utilised to compute the alpha co-efficient for internal consistency. An overall reliability co-efficient of 0.72 was established.

A subsequent reliability check was conducted on a sample of 2740 husbands and wives, which was sub-divided into two samples (sample 1, N = 1330; sample 2, N = 1410). Reliability co-efficients of 0.79 and 0.82 were obtained for samples 1 and 2 respectively. A further reliability check on the total sample (N = 2740) revealed an overall scale reliability of 0.81. Reliability checks for the subscales appeared to be less stable, with scores ranging from 0.30 to 0.73 (McCubbin and Patterson 1991).

Test-retest reliability conducted four to five weeks apart on 150 respondents in 1981 revealed percent agreement on individual items, ranging between 0.72 and 0.77, and total scale reliability of 0.80, thus indicating acceptable reliability over time (McCubbin and Patterson 1991)

4.6.2.1.6 Validity

A validity check was conducted by utilising discriminant analyses between low and high conflict families who had a child with cerebral palsy or myelomeningocele. The results revealed that high conflict families with a child with cerebral palsy experienced a significantly higher pile-up of life changes in three areas: intra-family strains, work-family transitions and strains, and total life changes. Similar significant differences with intra-family strains and total life changes, discriminated high conflict and low conflict families with a myelomeningocele child (McCubbin and Patterson 1991).

A further validity assessment of FILE was conducted by correlating ten scales from FILE with a family functioning measure, the Family Environment Scale (FES)(Moos, 1974). As predicted by the researchers, total recent life changes correlated negatively with the FES dimension of cohesion ($r = -0.24$), independence ($r = -0.16$) and organization ($r = -0.14$), and correlated positively with conflict ($r = +0.23$). Therefore, moderately high correlations between the intra-familial scale of FILE and six indices of family functioning (FES) were supportive of its construct validity (McCubbin and Patterson 1991).

The predictive validity of FILE was assessed by correlating categories of FILE with the changes in health status (such as lung function) of children with cystic fibrosis (N = 100). A number of family stressors and strains in a 12 month period were associated with a subsequent decline in the children's lung functioning. A total pile-up of family life stressors was significantly and inversely correlated with the measure of health status ($p < 0.05$; $p < 0.01$), thus confirming its predictive validity (McCubbin and Patterson 1991).

4.6.2.2 Family Inventory of Resources for Management (FIRM)

4.6.2.2.1 Introduction

In the attempt to assess the family's repertoire of resources, the Family Inventory of Resources for Management (FIRM), (McCubbin et al. 1980) was developed. To enable predictions to be made about how a family adapts to stressful events, the resiliency model requires information about the resources a family has available. Therefore, it may be hypothesised that families possessing a larger repertoire of resources will manage more effectively and will be better able to adapt to stressful situations (McCubbin and Comeau 1991).

4.6.2.2.2 Description

FIRM is a 69-item self-report instrument designed to assess a family's social and psychological resources and their social support dimensions. The selection of items for FIRM was influenced by literature and theory (as discussed in the

previous chapter) in three major areas, viz., personal resources, the family system internal resources, and community support. Although FIRM was developed utilising a population experiencing chronic illness, the items were designed for use with any type of family.

FIRM provides an index of a family's repertoire of resources at any point in time. When viewed with family life changes and family coping processes, it allows the operationalisation of factors in the resiliency model. An assessment of outcome related to family adaptation may then be predicted (McCubbin and Comeau 1991).

4.6.2.2.3 Conceptual Organisation

The instrument is conceptualised according to four scales:

- Scale I Family Strengths I - Esteem and Communication (FS I): The fifteen items of this scale reflect the presence of a combination of personal, family system and community resources in six areas:
  a) family esteem: respect of significant members, including friends and co-workers;
  b) communication: involves the sharing of feelings, discussing decisions;
  c) mutual assistance: helping significant members;
  d) optimism: maintaining a positive outlook;
  e) problem-solving ability; and
  f) encouragement of autonomy among members.

- Scale II Family Strengths II - Mastery and Health (FS II): This family resource includes twenty items that

relate to resources along three dimensions:

a) sense of mastery over family events and outcomes (managerial ability, flexibility, fate control);

b) family mutuality (emotional support, cooperation, togetherness); and

c) physical and emotional health.

- Scale III Extended Family Social Support (EFSS):
  This family resource index contains four items which indicate mutual help and support received and given to relatives.

- Scale IV Financial Well-Being (FWB):
  The sixteen items reflect the family's perceived financial efficacy along the dimensions of:
  a) ability to meet financial commitments;
  b) adequacy of financial reserves;
  c) ability to assist others (outside the family);
  d) optimism about the family's financial future, (for example, adequacy of insurance, present and retirement income, employment benefits, and future progress) (McCubbin and Comeau 1991, McCubbin and Thompson 1991).

FIRM contains two additional indices which are not considered major dimensions or subscales of the total measure. These are:

- Scale V Sources of Financial Support Index (SFS):
  The seven items reflect the sense of esteem and stability associated with income.

  This is an additional index related to Financial Well-Being. The parent's education may be an additional consideration along with the social-psychological dimensions assessed by FIRM (McCubbin and Comeau 1991).

- Scale VI Social Desirability (SD): Seven items represent socially desirable responses. An example of such an response might be, "we feel our family is a perfect success."

4.6.2.2.4 Administration and Scoring

The family member is asked how best a statement describes their family, and to record their response on a 0-3 point rating scale, ranging from "not at all" to "very well."

FIRM may be scored by adhering to specific scoring procedures. Firstly, certain items require the reversal of scores. Secondly, a number of items require changing to a 2-point rating scale. Finally, the scores rated on the remaining items are then added. A total score for each scale is obtained by adding the individual item scores of each scale. A total FIRM score is obtained by adding the first four scales, i.e. scales 1, 2, 3 and 4. The remaining scales (scale 5 and 6), are added to provide the researcher additional information (McCubbin and Comeau 1991). Normative data are available for FIRM (McCubbin and Patterson 1991).

4.6.2.2.5 Reliability

Data from 322 families having children with cerebral palsy and myelomeningocele were computed to reveal an internal consistency reliability for the four scales of 0.89 (Cronbach's Alpha). The internal reliability for the individual scales has been established as follows,

Scale I = 0.85;
Scale II = 0.85;

Scale III = 0.62;

Scale IV = 0.85 (McCubbin and Comeau 1991). Good reliability and stability of the four scales has thus been established.

Furthermore, an intercorrelation matrix of the FIRM scales was examined; the scales were found to correlate moderately at the 0.001 level of confidence (see Table 4)(McCubbin and Comeau 1991).

Table 4 : Intercorrelation matrix of FIRM scales (McCubbin and Comeau 1991)

FIRM scales	FS I	FS II	EFSS	FWB	SFS	SD
FS I	-	0.29***	0.37***	0.29***	-0.01	0.48***
FS II	0.29***	-	0.27***	0.28***	0.17***	0.46***
EFSS	0.37***	0.27***	-	0.19***	0.05	0.23***
FWB	0.29***	0.28***	0.19***	-	0.38***	0.18***
SFS	-0.01	0.17***	0.05	0.38***	-	-0.002
SD	0.48***	0.46***	0.23***	0.18***	-0.002	-

$p < 0.001$

The sources of financial support and the social desirability index have not been included in the factor analysis because of the dichotomous nature of the items. The sources of financial support scale is an additional guide and may be useful when examined along with the actual income of the family. Although the reliability of this scale was found to be low (alpha = 0.44), the source of family income has been recommended as useful information. Reliability co-efficients are not available for the social desirability scale, which was added to the FIRM to give the researcher

additional information (McCubbin and Comeau 1991).

4.6.2.2.6 Validity

Factor analytic procedures were used on the data from 322 families with a chronically ill child to determine the underlying dimensions of the instrument. The data were used in establishing factor loadings for each of the 69 items on the scale (McCubbin and Comeau 1991). The two additional factors (sources of financial support and social desirability) are not considered major dimensions of the scale, and therefore were not assigned factor loadings (McCubbin and Comeau 1991).

A further validity assessment was conducted by correlating FIRM scales with selected FES (Moos 1976) scales (Comeau 1985). The data demonstrated significant positive correlations between the FIRM and the family environment dimensions of cohesion ($r = 0.46$, $p < 0.001$), expressiveness ($r = 0.27$, $p < 0.001$) and organisation ($r = 0.25$, $p < 0.001$), and negative correlations between family conflict and FIRM ($r = -0.30$, $p < .001$; $p < 0.01$). These associations between family resource and desirable family functioning offer support for the validity of FIRM (McCubbin and Comeau 1991).

Additional studies conducted on families who have a child with myelomeningcele and cerebral palsy reveal that low and high conflict families differ significantly in their levels of social-psychological resources, particularly in family strengths, ($p < 0.05$) (McCubbin et al. 1981, Nevin et al. 1981).

Further, Comeau (1985) found evidence in support of scale I (family strength I - esteem and communication) as an explanatory variable for the active health problems of myelomeningocele children. A similar study conducted by McCubbin (1986) revealed that financial well-being, a family resource variable, was the only predictor associated with active health problems in the mildly impaired myelomeningocele child.

4.6.3.3 Coping Health Inventory for Parents (CHIP)

4.6.2.3.1 Introduction

Parental coping is a critical aspect of family functioning in families with a chronically ill member. Managing the long-term treatment of a member with a chronic illness usually involves a complementary relationship between the health-care team and the family unit. The successful care of the chronically ill member depends on the family's willingness to modify family life in response to the often complex and time-consuming regimen of continuous therapy. Parental coping strategies employed to manage the strains are regarded as an important mediating and buffering influence to the impact of such demands.

4.6.2.3.2 Description

The Coping Health Inventory for Parents (CHIP) (McCubbin et al. 1979), a 45-item behaviour checklist, was developed to assess parents' perceptions of behaviours they are currently using to manage family life when they have a child member who is ill.

In order to describe or predict how a family adapts under a chronic stress situation, the resiliency model requires information about coping behaviours. It is hypothesised that families possessing a larger repertoire of coping behaviours will manage the situation of the ill child more effectively.

The construction of CHIP was influenced by the inclusion of behaviour items used in earlier studies of family response to stress (e.g. McCubbin et al. 1980), with additional behaviour items focusing on social support theory (Cobb 1976), family stress theory (Burr 1973) and theories of the individual psychology of coping (Lazarus 1966, Pearlin and Schooler 1978).

CHIP provides a measurement of how a parent copes in response to an illness and whether the specific coping behaviour has a positive or deleterious effect on the ill child or family unit (McCubbin 1991).

4.6.2.3.3 Conceptual Organisation

CHIP has been conceptualised according to three patterns:

- Coping I Family Integration, Co-operation and An Optimistic Definition of the Situation:

  This pattern is composed of nineteen coping behaviours that focus on the family and the parent's outlook on life and chronic illness. It also focuses on the strengthening of family relationships.

- Coping II Maintaining Social Support, Self-Esteem and Psychological Stability:

  There are eighteen coping behaviours in this pattern that focus on the parents' efforts to maintain a personal sense of well-being through obtaining social support, and maintaining identity and self-esteem. It also focuses on coping behaviours which enable the management of tensions, stress and pressures.

- Coping III Understanding the Health Care Situation Through Communication with Other Parents and Consultation with the Health Care Team:

  This pattern comprises eight coping behaviours directed at the parents' relationship with health professionals and with parents of other chronically ill children. The behaviours focus on the parents' efforts to understand the illness and to master the medical information needed to cope with the illness (McCubbin 1991).

4.6.2.3.4 Administration and Scoring

Utilising a scale of 0 to 3 (with 0 being "not helpful" and 3 being "extremely helpful"), the parent is asked to record how helpful each coping behaviour item is to them in managing the home-illness situation. If a particular coping behaviour is not used, the respondent records the reason why.

Coping scale scores for each of the three patterns can be computed by summing the respondents' "helpfulness" ratings across the behaviour items for each pattern (McCubbin 1991).

Comparative normative data have also been published (McCubbin and Patterson 1981).

4.6.2.3.5 Reliability

The psychometric properties of this instrument are encouraging (McCubbin 1991). In the initial study of 185 parents of children with cystic fibrosis, Cronbach's alphas were computed on the data for each coping pattern. The results indicated respectable internal reliability co-efficients of 0.79 (Coping Pattern I), 0.79 (Coping Pattern II) and 0.71 (Coping Pattern III) (McCubbin et al. 1979).

The intercorrelation matrix of the CHIP scales was examined and the scales were found to correlate moderately. According to McCubbin (1986) a moderate correlation may be expected with a instrument designed to measure dimensions of coping behaviours, which are, in fact, reality related.

4.6.2.3.6 Validity

Initial factor analytic procedures were used to determine the dimensions of parental coping, where the three coping patterns were found to represent 71,1 per cent of the variance of the original matrix (McCubbin et al. 1979, McCubbin and Patterson 1981)

Further correlation procedures were conducted on data utilising the FES (Moos 1976) on families of children with

cystic fibrosis. It was hypothesised that the coping patterns (CHIP) directed at maintaining family integration, strengthening self and understanding the heath care situation would be associated with the family dimensions (Moos 1976). The mother's use of coping patterns I and III were positively correlated with family cohesiveness ($r = 0.19$; $p < 0.05$); Coping Pattern II was positively correlated with family expressiveness ($r = 0.32$; $p = 0 < .01$). Thus, mothers' use of three coping patterns were validated by their positive association with family cohesiveness and expressiveness (McCubbin et al. 1983).

In another rigorous test of validity, parental coping as measured by CHIP, was validated against the health status indices. The study was conducted using data from a sample of 308 families who had a chronically ill child. Mothers' effort to maintain family integration, cooperation and an optimistic definition of the situation (coping pattern I) were validated against the criterion index of positive gains in the child's height and weight ($r = 0.20$; $p < 0.05$)). Coping pattern II - maintaining social support, self-esteem and psychological stability - was significantly correlated with positive changes in the pulmonary function index ($r = 0.23$; $p < 0.05$) (McCubbin 1991).

Additional validity checks using CHIP were conducted between low and high conflict families who had a child with cerebral palsy. Discriminant analyses revealed that mothers' use of all three coping patterns was significantly higher in high conflict families (McCubbin 1991). These findings are consistent with the theoretical understanding of coping. Coping behaviours are developed in response to stressful situations and high conflict in a family is one index of family stress. Consequently, one would expect mothers in high conflict families to record greater use of the coping

behaviours assessed by CHIP since this reflects an active effort on their part to manage the conflict and adapt to the situation.

The value of CHIP lies in its use with different disabling conditions. For example, two studies incorporated the comparison of mothers of well children with mothers of chronically ill children. The coping scores of mothers of children with seizure disorders were significantly higher on family integration (coping pattern I) and health care communication/consultation (coping pattern III) than the scores of mothers of well children (McCauslin 1984).

Significantly higher scores differentiated mothers of autistic and mentally retarded adolescents from mothers of normal adolescents (Donovan 1985). In families with a child with multiple disabilities, higher levels of family stressors were accompanied by lower scores reported on family resources and parental coping patterns (Murray 1983).

CHIP may also be sensitive to ethnic and regional differences in the samples. For example, American Black mothers of children with cardiac disease in the southern United States (Sterling 1985) found the coping behaviour "believing in God" extremely helpful.

Furthermore, coping data obtained from the administration of this instrument was both analysed as a dependent variable and also an independent variable correlated with other measures or indices of family functioning (Golden 1983, Gibson 1984, Brem 1985). Analysis of the efficacy of specific coping behaviours was also examined in several studies (Christiansen 1982, Moraiejo 1983). Correlation of parental coping with

other family variables, and coping with child factors were frequently reported lines of scientific questioning (Austin 1985, Sterling 1985, Golden 1985, Claybaugh and Schwab 1985, Murray 1983, Bode 1983).

CHIP, therefore, appears to provide a reliable and valid assessment of parental coping especially in the absence of locally developed measures.

4.6.2.4 Family Crisis Oriented Personal Evaluation Scales (F-COPES)

4.6.2.4.1 Introduction

According to McCubbin (1979) the active process of family adaptation involving coping strategies and family coping patterns in transactions with the community, has received limited attention in both research and theory building. The family is a reactor to the medical stressor and a manager of the resources within the family system. The construction of this instrument was influenced by Hill's (1949) original conceptualisation, Burr's synthesis (1973) and coping theory research (Lazarus 1966), as well as other coping inventories, such as the Family Coping Inventory (FCI) (McCubbin et al. 1981) and CHIP.

F-COPES was based on the assumption that family coping is not created instantaneously but is developed, shaped and modified over time. Such behaviours involve the simultaneous management of various dimensions of family life, inter alia,

- the maintenance of satisfactory internal conditions for communication and family organisation;
- promoting member independence and self-esteem;

- maintenance of family bonds of coherence and unity;
- maintenance and development of social supports in transactions with the community; and
- maintenance of some efforts to control the impact of the stressor and the degree of change in the family (McCubbin et al. 1991).

4.6.2.4.2 Description

Designed by McCubbin et al. (1981), F-COPES was created to isolate problem-solving and behavioural strategies employed by families faced with difficult situations.

F-COPES is a 30-item self-report instrument. It measures coping behaviours which pertain to the two levels of interaction as depicted in the resiliency model. These are :

- the individual to family system, or the ways a family handles difficulties or problems "internally" or amongst its members; and
- the family to social environment, or the ways the family handles problems "externally" or demands that emerge outside its boundaries but affect the family unit.

It is hypothesised that families operating with more coping focused on both levels of interaction will adapt to stressful medical situations more successfully (McCubbin et al. 1991).

The instrument was also designed to integrate some aspect of family resources (such as extended family and community support, and so on) and the appraisal (reframing, passivity, and so on) emphasised in the resiliency model. In drawing

upon the coping dimensions of the resiliency model, the following factors have been integrated: pile-up, family resources and meaning/perception.

4.6.2.4.3 Conceptual Organisation

This instrument has been conceptualised according to five coping patterns:

- Coping I Acquiring Social Support (ASS):

  This scale comprises 9 items which focus on family efforts to share concerns with others and to obtain emotional, esteem, and network support from relatives, friends, neighbours, and close friendships.

- Coping II Reframing (R):

  The 8 behaviour items in this scale focus on family efforts to redefine difficult situations into a more positive perspective, developing a sense of confidence and self-determination, and facing demands head on.

- Coping III Seeking Spiritual Support (SSS):

  This scale consists of 4 behaviour items which reflect family involvement in religious activities which include attending services, participation and seeking the counsel of a priest, and their cultural ideology in dealing with difficulties.

- Coping IV Mobilising Family to Acquire and Accept Help (MFAAH):

  The 4 behaviour items focus on the family's efforts to seek assistance. These behaviours underscore the importance of seeking professional counselling, community agency assistance, medical consultation, and accepting support from others in the community.

- Coping V Passive Appraisal (PA):

  This scale is represented by 4 behavioural items. It reflects the family's efforts (such as avoidance responses) to avoid demands, and consists of trusting luck to solve one's problems or allowing time to resolve issues. It further reveals a lack of confidence in one's ability to handle demands or altering outcome (McCubbin et al. 1991).

4.6.2.4.4 Administration and Scoring

The family member is asked how well an item describes his/her attitude and behaviour in response to problems or difficulties. Responses are rated on a likert-type scale consisting of five alternatives: "strongly disagree", "moderately disagree", "neither agree nor disagree", "moderately agree", or "strongly agree".

Numbers are assigned as scores to the response choices from one through five, with 1 being strongly disagree and 5 being strongly agree. Certain items require the reversal of scores. A sum score is obtained for each sub-scale and a total score by adding the respondent's scores for each item (McCubbin et al. 1991).

Normative data are available for F-COPES and for the five coping patterns (Olson et al. 1985).

4.6.2.4.5 Reliability

A large sample completed the instrument. It was divided into two separate samples (sample 1, N = 1338; and sample 2, N = 1244). Cronbach's alpha was computed for F-COPES, independently on both samples. The overall scale reliability co-efficient were 0.86 and 0.87, respectively, indicating a high reliability (McCubbin et al. 1991).

The indices of internal consistency for the five individual coping scales, computed on both samples independently were high, with Cronbach's alpha ranging from 0.64 to 0.84. Alpha reliability co-efficient for individual coping patterns for the combined samples were:

CP I	acquiring social support	: 0.83
CP II	reframing	: 0.82
CP III	seeking spiritual support	: 0.80
CP IV	mobilising family to acquire and accept help	: 0.71
CP V	passive appraisal	: 0.63

Test-retest reliability co-efficient (4 weeks apart) were computed for the total scale and the five coping patterns. The overall test-retest reliability for F-COPES was 0.81. High reliability co-efficients for individual coping patterns were obtained, ranging from 0.61 to 0.95 (McCubbin and Patterson 1981, Olson et al. 1985). The patterns "reframing"

and "passive appraisal" showed slightly lower test-retest co-efficient in comparison with other patterns, suggesting that the more concrete behavioural items such as "soliciting social support" provide more response consistency over time than factors relating to cognitive adjustment.

4.6.2.4.6 Validity

Validity studies were conducted using a large group of husbands, wives and adolescents (N = 2740). The group was divided into two samples. Factor analyses using varimax rotation were completed on the first sample. The factor structure was very similar to the initial factor analyses (conducted on a sample of 119 subjects), where each of the 30 items had a factor loading greater than 0.38, and reaching a co-efficient of 0.85 (McCubbin et al. 1982).

4.6.2.5 Rationale for the Selection of the Resiliency Measures

As indicated, a number independent studies and research conducted through the Family Stress, Coping and Health Project attest to the sound psychometric properties of the resiliency measures, making them acceptable for testing (Nevin et al. 1981, Murray 1983, McCauslin 1984, Donovan 1985, Sterling 1985, McCubbin et al. 1981, McCubbin and Thompson 1991, McCubbin and Comeau, 1991, McCubbin and Patterson, 1991).

Specifically, FILE is of value in that it measures "cumulative life changes" in the study of family behaviour in response to stress. Other life stress questionnaires are

available (for example, Schedule of Recent Experiences, Hawkins et al. 1957; Life Events Scale, Holmes and Rahe 1967; Life Experience Survey, Sarason et al. 1978). While they do note some events that pertain to family life, the focus of these instruments has been largely on the individual and his reaction to social and life stressors (Mullins et al. 1991). Hence, the use of FILE is an attempt to bridge family stress theory and stress-illness research.

To the author's knowledge there is a limited number of standardised tools which measure family resources. The Family Resources Index, used by Timko et al. (1992) is a combination of the FES (Moos 1974) and a subscale of the Health and Daily Living Form (HDL) (Moos et al. 1990). It was not designed for the assessment of families with chronic illness. FIRM, on the other hand, provides comprehensive information on the utilization and management of family resources during the experience of chronic illness.

The two coping measures (CHIP and F-COPES) have a particular advantage over the well-known Ways of Coping test, in that the former are designed to focus directly on individual coping efforts in specific situations. CHIP assesses parental coping specifically in the health and illness situation, while F-COPES measures family coping responses to illness. As indicated earlier, CHIP has also been successfully utilised in many scientific studies (e.g. Golden 1983, Brem 1985, Sterling 1985, Christiansen, 1982, Gibson 1985).

When administered as a battery, these family measures (FILE, FIRM, F-COPES and CHIP) allow the researcher the opportunity to operationalise factors of the resiliency model, recognising the multi-dimensionality of the family and child.

Therefore, as a deductive model, it enables the examination of the patterns of stress, resources, and coping processes. These critical dimensions are seen as necessary in the assessment of the family adaptation to chronic childhood illness, and in the application of health-care and illness research. Hence, this model is selected for the present research.

4.6.3 The Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS)

4.6.3.1 Introduction

As previously discussed, there are many variables that contribute to or ameliorate stress in families. The experience of chronic illness affects not only the ill child but the family members as well. It is therefore important to measure the different experiences of family stress.

4.6.3.2 Description

The Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS) (Holroyd 1987) is a 285-item true/false instrument. It has been designed to identify families who require assistance.

The QRS has been developed to:

- identify problem areas experienced by the ill child, as well as factors related to the care of the ill member;

- focus on factors that influence the family as a result of caring for a chronically ill child, such as the respondent's mental status, psychological variables and attitude;
- measure stress as it affects the integration and opportunities for the family.

The QRS is also available in a short form (66-items), but this was not used in the present research because of its poor psychometric properties (Holroyd 1987).

4.6.3.3 Conceptual Organisation

The QRS yields fifteen scales that cover three domains.

They are grouped as follows:

- Personal Problems Scales

  a) Scale 1. Poor Health/Mood:

  This 11-item scale reflects role discontentment, sadness, tension, fatigue and a feeling of pressure from taking care of the ill child. Elevations reflect an interaction between the child's illness and parents' expectations of what their own lives should be.

  b) Scale 2. Excess Time Demands:

  This scale comprises 14 items which measure the primary caretaker's difficulty or inability to have time to herself, and the difficulty of

enjoying employment and leisurely activities outside the home.

c) Scale 3. Negative Attitude toward Index Case:

This scale has 23 items a number of which focus on social sensitivity with a tendency to be concerned about what other people might think of the ill child and of the respondent. It also reflects a tendency to worry about the index child, where worry is manifested in issues about the child's future and possible death.

d) Scale 4. Overprotection/Dependency:

This scale, consisting of 13 items, measures dependency on the part of the ill child and overprotection on the part of parental or caretaker activities or behaviours.

e) Scale 5. Lack of Social Support:

Comprising 10 items, this scale reflects a shortage of organisational, community (including medical) resources, family non-involvement, lack of supportive friendships, and family disagreement over caretaking tasks. The scores tend to be higher for parents of children with life-threatening physical illnesses (Holroyd and Guthrie 1986).

f) Scale 6. Overcommitment/Martyrdom:

This short scale of 7 items focuses on overcommitment and absorbed involvement of parent with the ill child, in the belief that only she is able to care for the child. Age

correlations provide interesting information about the meaning of this scale. Correlations are negative for children with medical illnesses such as leukaemia, and positive for children with psychiatric conditions. Further, the younger the child with a life threatening illness the more the parent feels solely responsible (Holroyd and Guthrie 1979).

g) Scale 7. Pessimism:

The 13 items comprising this scale reflect an expectation of poor patient prognosis resulting in a worsening of the child's condition, and greater burdens for the family future. It also indicates that institutionalisation or living away from home is an option to be considered. Pessimism scores are elevated with the presence of severe disability and physical dependency (Holroyd and Guthrie 1986), and may reflect a realistic hopelessness in some medical conditions.

- Family Problem Scales

h) Scale 8. Lack of Family Integration:

This scale, comprising 23 items, focuses on family disharmony, lack of intrafamilial support, difficulty in including the ill child in family activities or in the cohesive family unit, and the presence of an atmosphere of rejection toward the identified patient.

i) Scale 9. Limits on Family Opportunity:

This short scale of 9 items is essentially

independent of the age of the child. It pertains to family members having to turn down opportunities for personal-growth, in the sphere of employment, education, and social activities. Scale 9 is independent of the severity of the child's condition (Holroyd 1987).

j) Scale 10. Financial Problems:

Scale 10 consists of 17 items reflecting adequacy of housing, income and the ability to provide the necessities for the identified patient. It does not correlate with the age of the patient.

- Problems of Index Case Scales

k) Scale 11. Physical Incapacitation:

Comprising 14 items, this scale is a robust measure of the ill child's physical problems and self-care skills. It pertains to the patient's ability to take care of physical needs such as feeding, toileting and ambulation, as well as the capability for normal sporting and other activities.

l) Scale 12. Lack of Activities for the Index Case:

This scale, although short (6 items) functions as a screening measure for individuals in need of an intervention program, such as a home activity schedule.

m) Scale 13. Occupational Limitations for Index Case:

This scale comprising 7 items reflects a concern about current opportunities for education and training as well as concerns about future employment opportunities for the child. Further, the older the child and the more severe the handicap, the more concern expressed, and the higher the score (Holroyd 1987).

n) Scale 14. Social Obtrusiveness:

The 7 item scale focuses on sensitivity to or concern about the opinion of others with regard to the child's unusual appearance or inappropriate behaviour.

o) Scale 15. Difficult Personality Characteristics:

Consisting of 32 items, this scale reflects personality and behavioral problems, and organic cognitive deficits. However, it is not a measure of retardation, as it is influenced by the social support the parents receive. For example, the more support they enjoy, the less burdened they are, and the fewer behaviour/personality or cognitive problems they report (Holroyd 1987).

4.6.3.4 Administration and Scoring

The questionnaire may be administered to any member of the family other than the ill person. The respondent is read the covering instructions by the researcher. Instructions are given to answer each question "true" or "false" as it applies

to respondent, their family, or the chronically ill child. The subject is encouraged to give honest feelings and opinions, and to respond to all items.

Scoring is facilitated using scoring templates. One point is counted for each item in the direction indicated by the individual scoring templates. A score is obtained for each of the 15 scales by summing these points.

Normative data based on mothers and fathers of 107 normal children from California (Holroyd 1986), parents of 44 normal children from Georgia, USA, (Patten 1986), and 42 normal (well) children from New Zealand (Wilton and Renault 1986) are available (Holroyd 1987). Special norms are also available for children with developmental disabilities, psychiatric problems, medical illnesses and neurological disease (Holroyd 1987).

4.6.3.5 Reliability

The reliability of the QRS has been well documented (Holroyd 1987). The Kuder-Richardson reliability co-efficient was used to measure internal consistency or unidimensionality. Median coefficients are noted for each of the fifteen scales:

Scale	Number of Items	Reliability estimate
1	11	0.79
2	14	0.73
3	23	0.81
4	13	0.67
5	10	0.23
6	7	0.28
7	13	0.65

8	23	0.78
9	9	0.69
10	17	0.74
11	14	0.61
12	6	0.63
13	7	0.41
14	7	0.24
15	32	0.88

(Holroyd 1987).

The longer scales tend to have higher co-efficient than the shorter ones, reflecting the increased stability with a greater number of items (Brown 1983). As stated by Lazarus et al. (1985), "the scales reflect the response of an individual to potentially stressful events, which is desirable in research on stress" (Holroyd 1988 p 336). The Kuder-Richardson internal consistency for the 285-item instrument is high, with a co-efficient of 0.96.

Test-retest reliability co-efficients are not available (Holroyd 1987).

Very low reliability is documented for the short-form QRS (QRS-S) (Holroyd 1988).

4.6.3.6 Validity

Research on the validity of the QRS began with construct validation of the internal structure of the test. Moderate to high correlation of 11 factors correlated with the 15 scales. While two different factor analytic procedures

yielded the same number of factors, (Ogura et al. 1980, Holroyd 1987) a detailed comparison of the factor structures has not, to the author's knowledge, been carried out.

Validity studies have demonstrated the effectiveness of the QRS in differentiating groups representing different populations and cultures, and different diagnosis and handicapping conditions (e.g. Kodaki and Inanami 1978a, Kodaki and Inanami 1978b, Beckman 1983, Holroyd and Guthrie 1986).

In one of the validation studies of the QRS, Holroyd et al. (1975) tested 28 mothers and 22 fathers of 29 autistic children. Mothers who were rated in the top quartile by interview scored higher on five QRS scales (scales 5,7,8,9, and 10) than did mothers in the lowest quartile. The scales that differentiated the two groups are in the areas of family problems and personal problems. None reflect severity of impairment in the index scales. As expected, families whose autistic children were institutionalised experienced less stress overall.

Most of the criterion validation research done to date has been concerned with various disabilities (Brown 1977, Bristol 1979, Murphy 1980, Friedrich and Friedrich 1981, Beckman 1983). Holroyd and Guthrie (1979) published research conducted with parents of children with neuromuscular disease and children seen in a psychiatry out-patient clinic. Discriminant analysis classified 85 per cent of cases into correct groups using the physical incapacitation scale alone. In another study, Holroyd and Guthrie (1986) compared parents of children with neuromuscular disease, cystic fibrosis and renal disease with parents of normal (control) children. As mentioned in the review of the literature, the three clinical

groups were found to exhibit different patterns of stress, consistent with the nature of their illness and requirements for care imposed on their families.

These studies have demonstrated that the QRS is valuable in discriminating populations that differ in diagnosis, degree of handicap, parent attributes, and community resources available (Holroyd 1987). In addition, the above studies demonstrate its validity on children and adolescents.

According to the authors, an external criterion validity study has not been feasible because there is no well-established test of stress in families caring for chronically ill and handicapped members, against which to validate the QRS (Brown 1983, Holroyd 1987).

Several studies have demonstrated cross-cultural validation of the usefulness of the QRS (Kodaki and Inanami 1978b, Patten 1983, Gildden 1986, Wilton and Renault 1986). The most extensive validation studies outside the Holroyd laboratory have been conducted in Japan. Kodaki and Inanami (1978a) translated the QRS into Japanese and administered it to parents of mentally retarded children. Few differences were found between the Asian and American samples, which led to the conclusion that the stress on parents caused by their handicapped children is universal beyond a few socio-cultural differences.

4.6.3.7 Rationale for the use of the Questionnaire on Resources and Stress (QRS)

The foremost reason for the selection of the QRS in this

investigation is that it allows the researcher to evaluate cause and effect and measure stress within the family system despite the interactions among child, parent and family variables. Therefore, the QRS provides "an opportunity for phenotypic description of these interacting variables when one family member is severely ill" (Holroyd 1988 p 336). It has an added value in that it offers a measurement of the stress related to the severity of illness and incapacitation, as well as the psychosocial potential of the ill child. Furthermore, a "QRS profile analysis may contribute to greater understanding of the problems faced by families than single stress indicators would provide" (Holroyd 1988 p 345).

As indicated earlier, the QRS is recognised as a sound psychometric research tool. Additionally, independent studies have empirically demonstrated the multi-dimensional nature of the QRS in following a range of scientific inquiries, and its usefulness in discriminating populations that differ in diagnosis and family attributes (Glidden 1986, Wilton and Renaut 1986, Holroyd and Guthrie 1986, Wikler et al. 1986, Inanami et al. 1980, Murphy 1980, Kodaki and Inanami 1978a, Kodaki and Inanami 1978b). It is also not limited cross-culturally.

4.6.4 The Kidcope

4.6.4.1 Introduction

Coping has been recognised as an important mediator of the impact of minor and major stressors on the short-term and long-term adaptation of chronically ill children (Lazarus and Folkman 1984). However, there have been few systematic efforts to design psychometrically sound measures to assess

children's coping (Curry and Russ 1985). The Kidcope was developed in response to this need (Spirito et al. 1988).

4.6.4.2 Description

The Kidcope (Spirito et al. 1988, Spirito et al. 1990) (Appendix B), is a checklist designed to assess behavioural and cognitive strategies in children. There are two versions of the scale. The longer version is applicable to children aged 13 to 17 years. The version used in this study was designed for children between the ages of 7 and 12 years. According to the authors, this was achieved by simplifying the language and shortening the items of the adolescent version.

4.6.4.3 Conceptual Organisation

The Kidcope has fifteen items that pertain to ten coping strategies. These are:

- Distraction (D), (2 items)
- Social Withdrawal (SW), (2 items)
- Cognitive Restructuring (CR)
- Self-criticism (SC)
- Blaming Others (BO)
- Problem-solving (PS), (2 items)
- Emotional Regulation (ER), (2 items)
- Wishful Thinking (WT), (2 items)
- Social Support (SS)
- Resignation (RES)

4.6.4.4 Administration and Scoring

The Kidcope may be administered to children individually or in a group. During the administration of the Kidcope, the child is requested to indicate a problem recently experienced with his illness. They are required to rate their responses to a coping item, according to whether they use a particular coping strategy (Frequency Scale) and how effective they believe it is for them (Efficacy Scale). The frequency scale is answered "yes", indicating the strategy was used, or "no" indicating the strategy was not used. The child indicates his response on the efficacy scale by selecting one of three likert-type responses (i.e. "not at all", "a little", and "a lot").

Before the first item is completed, the researcher should re-emphasise that the scale items will be completed in reference to the chosen problem. The child is reminded about the problem he has specified throughout the task.

This scale is completed in an interview style. The researcher is encouraged to explain to the child those items that he does not understand, and must ensure his or her complete understanding of the responses by each child.

The frequency scale is scored by allocating a score of 1 for a "yes" response and a score of 2 for a "no" response. The responses on the efficacy scale are allocated the following scores: "not at all" = 0; "a little" = 1; and "a lot" = 2. For those coping strategies that have two items for each coping strategy, a score of 1 is given to the frequency scale if one of the items is rated "yes." If both items have been answered "no", then the frequency scale is scored 0. If a

child uses either item in a category then the child is rated as having used that coping category. If 2 items in a category are chosen, the highest efficacy rating selected by the child is scored (Spirito et al. 1988).

Since the present research is concerned with the coping strategies used by children, only the frequency scale will be examined.

4.6.4.5 Reliability

Reliability studies were conducted by Spirito and others (1988), with a number of normal samples and paediatric patients. Sample A comprised 60 children ranging from 15 to 18 years. The Kidcope was administered to them on two occasions separated by 3 days. On the second administration, the subjects were asked to recall the stressor they described three days earlier and complete the Kidcope according to how they coped with the event. Pearson test-retest correlations revealed moderate to high co-efficients, ranging from 0.56 to 0.74, thus indicating good reliability for short periods.

A test-retest reliability study was conducted on 42 subjects. These subjects completed a Kidcope questionnaire 1 week following the original administration. Moderately high correlations were obtained with the same personal stressor, with scores ranging from 0.41 to 0.83. A low correlation was obtained for blaming others, viz. 0.07. The authors indicate that the low score may reflect that, in the week following the event, the subjects may have been more able to view the situation rationally, and may have been less prone to use the blaming others strategy (Spirito et al. 1988).

A subsequent study was conducted on 142 ninth-graders. They were administered the Kidcope on two occasions separated by 10 weeks. The students selected a personal event with which they had been coping within the preceding month. As expected, the obtained correlations are lower than those obtained for shorter periods, with co-efficients ranging from 0.15 to 0.43. The authors concluded that the results support the assumption that coping is a process that changes over time and according to situational demands (Spirito et al. 1988). Thus, a high correlation co-efficient on a test-retest format may not be the most appropriate indicator of the soundness of a coping instrument (Mash and Terdal 1984, Stone and Neale 1984).

Internal consistency was measured for the different strategies. Moderately high scores were obtained for problem-solving, social support and distraction ($r = 0.67$; 0.63 and 0.62, respectively). Somewhat lower correlations ($r = 0.22$, 0.31, and 0.42) were obtained for avoidance, blame and wishful thinking.

The utility of the Kidcope was also demonstrated by administering the scale to samples of children with physical illness. One sample ($N = 38$) comprised children, aged 10 to 18 years with various medical diagnoses such as abdominal pain ($N = 6$), inflammatory bowel disease ($N = 5$), headaches ($N = 7$), cancer ($N = 3$), encopresis ($N = 3$), haemophilia ($N = 2$), different pain complaints and other problems such as sleep disorders and seizures. The patients were asked to complete the Kidcope in response to a specific stressor associated with their illness. Results indicated that distraction was the most frequently employed coping strategy used by clinical groups.

A further reliability study was conducted using the data from a sample of fourth to eighth graders (N = 560), aged 9 to 14 years. It revealed moderate to high reliability co-efficients over a one week and two week period for the Kidcope items. The phi-coefficients obtained were:

distraction, r = 0.13, r = 0.49;
social withdrawal, r= 0.45, r = 0.37;
cognitive restructuring, r = 0.39, r = 0.16;
self-criticism, r = 0.63, r = 0.38;
blaming others, r = 0.79, 0.37;
problem-solving, r = 0.62, r = 0.18;
emotional regulation, r = 0.61, 0.49;
wishful thinking, r = 0.80, r = 0.31;
social support, r = 0.59, r = 0.64; and
resignation, r = 0.20, r = 0.46.

Again, these findings establish the reliability of this measure (Spirito et al. 1992).

4.6.4.6 Validity

Initially the scale items were generated to tap coping styles delineated in factor analytic studies of older coping scales (Billings and Moos 1981, Stone and Neale 1984). The scale, administered to 134 ninth-grade students, was then factor analysed using a principal factor analysis rotated to a varimax solution. Six factors were finally selected resulting in a total of 13 items. Subsequent development resulted in the briefer, conceptually clearer scale (Spirito et al. 1988).

The concurrent validity of the Kidcope was further established by making comparisons with previously standardised measures of coping: the Coping Strategies Inventory (CSI) (Tobin et al. 1984) and the Adolescent Coping Orientation for Problem Experiences Inventory (A-COPE) (Patterson and McCubbin 1983).

The first sample comprised 91 children in four classes with a mean age of 14,4 years. Two of the classes were initially administered the CSI and Kidcope. The sequence of the two scales was counter-balanced to control for order effects. Factor analyses revealed an eight factor solution including problem-solving, cognitive restructuring, emotional expression, problem avoidance, social support, wishful thinking, social withdrawal, and blame. The highest correlations were obtained between seven of the eight predicted subscales of the CSI and the corresponding Kidcope items. The results revealed that most of the higher correlations between the scales were obtained between the predicted factor scores of the CSI and the Kidcope items (moderately to high range = 0.33 to 0.77). This was predicted since the primary coping strategies of the CSI are quite similar and based on the same conceptual reasoning as those of the Kidcope (Spirito et al. 1988).

The 49 students in the remaining two classes completed the Kidcope and the A-COPE. Since the subjects in the study were adolescents, the relationship between the factor scores of the A-COPE and the items of the Kidcope was also examined. The resulting correlations ranged from 0.08 to 0.62. This was expected, however, as the factor scores of the A-COPE are less congruent with the ones chosen for the Kidcope. High correlations between the two scales tended to be on items that were conceptually similar and low correlations between those conceptually dissimilar. For example, a high

correlation (r = 0.62) was obtained on the "seeking diversions" subscale of the A-COPE (Spirito et al. 1988).

4.6.4.7 Rationale for the selection of Kidcope

There are a number of advantages for the choice of the Kidcope as a coping measure. As delineated earlier in this paper, the instrument is based on the most commonly agreed framework (Lazarus and Folkman 1984) for predicting individual coping in highly defined contexts such as clinical situations (Compas 1987). Its short and simple format of fifteen items makes it an ideal measure for use with children. It is of value in that it taps both cognitive and behavioural coping strategies. Furthermore, it allows cross-situational investigations of age and sex differences in coping. Additionally, the reliability and validity studies contribute to its psychometrically sound properties. As indicated, subsequent research has further substantiated the Kidcope's utility for examining coping strategies (Spirito et al. 1989, Spirito et al. 1992), leading researchers to conclude that "the findings regarding the reliability and validity of the questionnaire and its ability to discriminate among responses of clinical populations have been quite encouraging" (Knapp et al. 1992 p 28).

Most importantly, Kidcope has been documented as the most frequently used and extensively researched coping questionnaire for use with children (Knapp et al. 1992, Stark et al. 1989, Spirito et al. 1988, Spirito et al. 1989).

Well-developed coping measures, such as the Ways of Coping (Aldwin et al. 1980) are fairly long and designed for use with an adult population. A review of the coping assessment

techniques for use in research with children and adolescents reveals a very limited array of instruments. These include projective techniques (e.g. Robins 1987, Walker 1988), behavioural observation scales (Curry and Russ 1985, Hubert et al. 1988), questionnaire methods (Elwood 1987, Compas et al. 1988), and interviews (e.g. Band and Weisz 1988).

Questionnaire methods provide a simple and systematic measure for use with children (Gil et al. 1991). However, while Elwood's questionnaire method is a well researched measure (Elwood 1987), it is limited in terms of its use with younger population. Hence, the Kidcope is the ideal choice for the assessment of children's coping over different stressors.

4.6.5 The Self-Perception Profile for Children (What I Am Like)

4.6.5.1 Introduction

The development of this scale (Harter 1978, Harter 1981a, Harter 1983, Harter 1985) was strongly influenced by Harter's interests in developing a model of competence motivation. The emphasis was on the child's perception of his or her competence. The relationship between this perception and the child's actual competence was viewed as an empirically interesting question in itself. Harter also proposed that children not only make discreet judgements about their competence in different domains, but that they also have a view of their general self-worth as individuals over and above specific competence judgements. The development of this rationale places the emergence of the self-theory around the age of 8 years. In other words, the child is able to make this judgement from about the age of 8 years. In

addition to these theoretical considerations, Harter was concerned about psychometric problems which have plagued existing measures of self-esteem.

4.6.5.2 Description

Developed by Susan Harter (1985), the Self-Perception Profile for Children, entitled "What I Am Like," is a 36-item questionnaire (Appendix C). The scale is designed to measure a child's self-perception of competence and overall self-worth. It represents a revision of the Perceived Competence Scale for Children (Harter 1979, Harter 1982). The original instrument tapped three competence domains, viz. cognitive, social and athletic, as well as global self-worth or self-esteem. The revised scale comprises two new subscales which have been added to the original four. These two subscales are physical appearance and behavioural conduct.

4.6.5.3 Conceptual Organisation

The scale comprises six subscales with 6 items each, tapping five specific domains, and global self-worth:

- Scholastic Competence:
  This scale is designed to tap the child's perception of his competence or ability within the realm of scholastic performance.

- Social Acceptance:
  This domain reflects the degree to which the child is accepted by peers or feels popular. The items do

not tap competence directly as they do not refer to social skills.

- Athletic Competence:
  This scale focuses on the child's perception of his competence in sports and outdoor games.

- Physical Appearance:
  This scale reflects the child's perception of his physical characteristics, and the degree to which the child is happy with his looks.

- Behavioural Conduct:
  Behavioural conduct focuses on the extent to which children like the way they behave, and act the way they are supposed to.

- Global Self-Worth:
  The items in this scale tap the extent to which the child likes himself as a person, is satisfied with the way he leads his life, and is generally happy. This scale constitutes a global judgement of one's worth as a person, rather than domain-specific competence or adequacy (Harter 1985).

4.6.5.4 Administration and Scoring

The scale may be administered in groups as well as individually. Each child is asked to choose which of two statements is most like their perception of themselves. For example "Some kids are happy with the way they look" but "other kids are not happy with the way they look." Having made this decision, the child decides whether the description is "sort of true" or "really true" for him or her.

Each item is scored from 1 to 4, where a score of 1 reflects low perceived competence and a score of 4 indicates high perceived competence. Scores are added and then averaged for each subscale. High scores reflect a positive sense of competence and self-worth. Normative data are provided for this instrument (Harter 1985).

4.6.5.5 Reliability

Subscale reliability was assessed by computing a co-efficient which provided an index of internal consistency. Reliability co-efficients were analysed using a sample of 341 children in the third through sixth grades. Values of 0.76, 0.78, 0.83 and 0.73 were obtained for the cognitive, social, physical and general sub-scales. Subsequent reliability studies conducted on three different samples of same-aged children (N = 714; N = 470; N = 746), revealed values ranging from 0.75 to 0.83, 0.75 to 0.84, 0.77 to 0.86 and 0.73 to 0.82 for the four scales respectively.

Intercorrelational assessment revealed that the correlations of the general self-worth subscale with each of the three competence subscales consistently tended to be among the highest, in the range of 0.40 and 0.58. The social and physical subscales are highly stable across samples, within the range of 0.46 and 0.58. The relationship between the cognitive subscale and both the social and physical subscale tend to be slightly lower, with some sample variation (Harter 1982).

Test-retest reliability data were collected from a sample of 208 pupils retested after 3 months, and a sample of 810 pupils retested after 9 months. These correlations,

corrected for attenuation, were 0.78, 0.80, 0.87 and 0.70 (first group), and 0.78, 0.75, 0.80 and 0.69 (second group), for the four subscales. The above findings demonstrate high reliability of the Harter scale (Harter 1982, Harter 1983).

4.6.5.6 Validity

Validity studies have been reported on the earlier version of the scale (the Perceived Competence Scale) (Harter 1979). The original factorial validity studies were conducted on a sample of approximately 2700 children in grades three to six. Mean and standard deviation scores have been reported. The factorial pattern of the scale has been stable across the grades, while factor analytic studies conducted on 748 children revealed clear and discrete factors for the two new subscales, which were (Harter 1983).

Factorial validity studies were conducted on samples A (N = 341 third to sixth grader scholars), B (N = 714 third to sixth graders) C, (N = 470 third to sixth graders) and D (N = 746 third to ninth grade students). Both orthogonal and oblique solutions were obtained revealing the same stable factor structure. For example, for sample B the average loading of items on their designated factors were 0.67, 0.61, 0.64 and 0.50 for the cognitive, social, physical, and general subscales, respectively. Separate analyses by grade have revealed that the factor pattern is very stable across grades 3 to 6. Congruence co-efficients to assess the correlation between factor loading across samples were calculated between each grade in sample D, for each factor separately. The values obtained ranged from 0.69 to 0.90 for the fourth through ninth grades. Third grade values were slightly lower, from 0.61 to 0.83. Overall grade comparisons revealed that the average congruency co-efficients were 0.83

for cognitive, 0.74 for social, 0.80 for physical and 0.76 for the general subscale. The same factor pattern emerged with average loadings of 0.57, 0.43, 0.53 and 0.48 for items on their designated factors on the four subscales respectively (Harter 1982).

The above studies demonstrate a highly stable factor pattern. "The very clear and stable factor structure reveal that children as young as 8 make meaningful differentiations..." (Harter 1982 p 95).

Clear support for construct validity was obtained from the correlations between perceived cognitive competence and the three motivational subscales on a measure of intrinsic versus extrinsic orientation (Harter 1981b).

Perceived competence was strongly related to preference for challenge ($r = 0.57$) and to independent mastery ($r = 0.33$). Higher order factoring revealed that perceived cognitive competence, challenge, independent mastery and curiosity form a distinct factor with very high loadings of 0.76, 0.87, 0.80, and 0.79 respectively (Harter 1982).

Discriminant validity was demonstrated for the cognitive domain with the prediction that learning-disabled children would rate their competence lower than normal children of the same age and grade, and that this difference would be most pronounced in the cognitive area. Results indicated a significant difference ($t(38) = 2.9$, $p < .005$), for the perceived cognitive competence ratings (mean = to 1.9 for learning disabled children ($N = 20$) compared with 2.8 for normal children ($N = 20$)). The social, physical and general self-worth ratings were also lower, although these

differences did not reach acceptable levels of significance. Discriminant validity for perceived social and physical competence was demonstrated when pupils selected for the sports team (N = 23) achieved higher scores in these domains than their classmates (N = 57)(t (78) = 3.4 and 2.5, $p < .001$ and $p < .01$, respectively) (Harter 1982).

4.6.5.7 Rationale for the selection of the Self-Perception Profile for Children

The Self-Perception Profile for Children was chosen over older and more commonly used instruments such as the Coopersmith Self-Esteem Inventory (Coopersmith 1967) and the Piers-Harris Self-Concept Scale (Piers 1977), because it has a number of advantages over these instruments, the most significant being that these older instruments provide only a single self-concept score.

This scale, in contrast, acknowledges the multi-factorial construct of a child's self-esteem (Harter 1983), and presents a comprehensive profile of the child's perceived competencies, distinct from overall self-worth, allowing for a richer picture of the child. Such an approach remains theoretically consistent with the developmental perspective delineated earlier in this thesis.

Furthermore, the correlation between the ratings from the original Harter scale and a children's social desirability scale (Crandall et al. 1965) is 0.09 against a correlation of 0.33 between the Coopersmith Self-Esteem Inventory and the Crandall Scale (Harter 1982).

Additionally, the new "structured alternative formate" (that is, four response alternatives) effectively reduces the child's tendency to give socially desirable responses.

The instrument is not only a relatively short assessment tool for use with children, but, as demonstrated earlier, it is both conceptually and empirically sound (Harter 1982, Harter 1985) and has been utilised in a number of investigations (Harter and Zumpf 1986, Silon and Harter 1985, Harter and Hogan 1985, Harter 1985, Renick 1985, Harter and Pike 1984).

4.7 The Testing Procedure

Initial contact with each mother was made in the paediatric clinics of the two hospitals. They were approached by the present researcher, who introduced herself as a clinical psychologist conducting research through the University of Natal. The mothers were informed about the nature and reason for the study: namely, that it would assist in the understanding and identification of the stress experienced, and coping patterns utilised by families and children experiencing chronic illness. They were informed that the results of the investigation would enhance the understanding of coping processes utilised by such children and families and could lead to effective intervention programmes which would ultimately benefit chronically ill children and their families. They were also informed about the confidentiality of the study and that their participation in or discontinuation with the research would in no way affect their children's treatment.

Mothers and children who agreed to participate in the investigation were seen individually. The testing procedure

began with a semi-structured interview where rapport was established. Items from the test questionnaires were read out individually to each subject, and were ticked off by the researcher. This was done to ensure that the participants understood each item. The total testing time comprised approximately two hours which included the testing of the child. The time spent in testing the child was 15 minutes. To reduce testee fatigue, the assessment comprised two sessions, the first being at the clinic and the second at the subject's home. The QRS was administered to the mother at home where the child was also assessed. This was done at the convenience of the subjects, and further reduced their travelling time and financial costs. Also, it assisted in creating a more comfortable testing environment as rapport was easily established before the testing of the child was undertaken.

In the asthma group, 8 parents refused to participate after completing the resiliency measures, for personal and social reasons. Additional patients were, therefore, recruited.

The instruments were administered to the mothers in the clinical and control groups, in the following order:

- the biographical questionnaire;
- FILE;
- FIRM;
- CHIP;
- F-COPES; and
- QRS.

The following instruments were administered to the children in the clinical and control groups:

- the Kidcope; and
- the Self-Perception Profile for Children.

4.8 Observations During Testing

Important information was obtained in the assessment of the three illness. Families of leukaemic and nephrotic syndrome children were enthusiastic, eager and most co-operative in completing the questionnaires. Many of these families were eager for the researcher to visit their homes and also to set up appointments after hours. One family, from Stanger, brought the entire family to the clinic. These families reported good relationships with their doctors, whom many of them revered. In contrast, families of asthmatics, while also at times hospitable, were very disgruntled, particularly with the care and treatment received from the hospital they visited. Their complaints were that they were not being listened to, and that the doctor had been aggressive rather than supportive. The group of children who had asthma also reported that their "greatest fear" was of the doctor treating them, rather than "injections" or "other" treatment. Such families also complained of a lack of social support.

Chapter 5 presents the results and statistical analyses of the data obtained from the investigation.

CHAPTER FIVE

RESULTS OF THE INVESTIGATION

5.1 Introduction

The data used in the analyses were obtained from the responses of the three chronic illness groups and the control group of non chronically ill paediatric out-patients and their parents to the battery of instruments described in the previous chapter. As mentioned earlier, the sample comprised asthmatic children (N = 30) and their mothers, leukaemic children (N = 23) and their mothers, nephrotic syndrome children (N = 22) and their mothers, and a control group of non chronically ill children (N = 30) and their mothers.

The data were subjected to the following types of analyses:

- Analyses of variance (ANOVA), to determine whether there were any significant differences in the stressors, resources or coping processes of the four groups. This is an appropriate measure for use with continuous variables and has the advantage of testing whether there are any differences between the groups with a single probability associated with the test.
- Where the overall F-test showed a significant difference between groups, Duncan's multiple range test was used as a post hoc test for pairwise comparisons. Duncan groupings having the same letter (A,B, etc) denote no significant difference between those groups.
- For categorical variables - that is demographic,

cultural and child variables - the chi-square test was used to compare the four groups.

- Comparisons were made between chronically ill and control groups, remission and induction sub-groups, and selected disease-related variables, the data of which were subjected to a number of t-tests and chi-square analyses.
- Pearson correlation co-efficients (r) were calculated for associations between continuous variables.

In computing statistical analyses the SAS Package 6.08 (1990) was used.

Throughout the study asterisks in the tables have the following meanings:

* P < 0.05
** P < 0.01
*** P < 0.001

When no asterisks appear, the value is not statistically significant.

5.2 Descriptive Statistics on Family Demographic and Cultural Variables

Table 5 : Distribution of sample according to demographic and cultural variables

	Asthma		Control		Leukaemia		Nephrotic		
N	30		30		23		22		
Variable	Freq	Percent	Freq	Percent	Freq	Percent	Freq	Percent	P Value
MARITAL STATUS:									
single	1	3.33	2	6.67	1	4.35	0	0.00	
married	23	76.67	27	90.00	21	91.30	20	0.91	
divorced	3	10.00	0	0.00	1	4.35	1	4.55	
widowed	3	10.00	1	3.33	0	0.00	1	4.55	
RELIGION:									
christian	6	20.00	6	20.00	4	17.39	4	18.18	
hindu	18	60.00	23	76.67	16	69.57	11	50.00	
moslem	6	20.00	1	3.33	3	13.04	7	31.82	
MATERNAL OCCUPATION:									
housewife	22	73.33	24	80.00	18	78.26	20	90.91	
skilled	3	10.00	4	13.33	2	8.70	1	4.55	
unskilled	2	6.67	2	6.67	1	4.35	1	4.55	
unemployed	3	10.0	0	0.00	2	8.70	0	0.00	
MOTHER'S EDUCATION:									
0	0	0.00	0	0.00	0	0.00	1	4.55	
<std 3	1	3.33	0	0.00	1	4.35	1	4.55	
std 3-4	4	13.33	0	0.00	1	4.35	3	13.64	
std 5-6	1	3.33	1	3.33	2	8.70	0	0.00	
std 7-8	13	43.33	12	40.00	6	26.09	5	22.73	
std 9-10	7	23.33	14	46.67	3	13.04	7	31.82	
>std 10	4	13.33	3	10.00	8	34.78	4	18.18	
degree	0	0.00	0	0.00	2	8.70	1	4.55	
primary school	26	86.67	27	90.00	13	56.52	17	77.27	
secondary school	4	13.33	3	10.00	10	43.48	5	22.73	0.016*
FAMILY STATUS:									
nuclear	13	43.33	18	60.00	17	73.91	16	72.73	
extended(wife's/	8	26.67	4	13.33	0	0.00	1	4.55	
husband's family)	9	30.00	8	26.67	6	26.09	5	22.73	
CULTURAL PRACTICES:									
sought assistance from priest	18	60.00	12	40.00	18	78.26	12	54.55	0.047*
conducted formal prayers	23	76.67	21	70.00	21	91.30	18	81.82	
punishment by God	9	30.00	5	16.67	6	26.09	9	40.91	
self-blame	9	30.00	6	20.00	4	17.39	3	13.64	
MARITAL PROBLEMS:									
closer to spouse	18	62.07	17	58.62	14	60.87	14	63.64	
marital problems	5	17.24	2	6.90	5	21.74	1	4.55	
MEDICAL KNOWLEDGE:									
	17	56.67	13	43.33	18	78.26	18	81.82	0.011*
SEVERITY OF CONDITION:									
no symptoms	4	13.33	19	63.33	18	78.26	15	68.18*	
symptoms-exer	9	30.00	5	16.67	2	8.70	4	18.18	
symptoms-rest	3	10.00	3	10.00	1	4.35	1	4.55	
PROGNOSIS:									
normal expect	13	43.33	20	66.67	10	43.48	11	50.00	
uncertain-hope	14	46.67	10	33.33	12	52.17	7	31.82	
uncertain-not hopeful	1	3.33	0	0.00	1	4.35	1	4.55	
progression	2	6.67	0	0.00	0	0.00	3	13.64	

* $p < 0.05$

Significant differences were noted on the following variables: mother's secondary school education, seeking assistance from priest, and medical knowledge. Significantly more mothers of leukaemic children than mothers in the three other groups had higher than a secondary level of education, sought assistance from a priest and had indicated that their children had no symptoms. Significantly more mothers of nephrotic children than mothers in the other groups had knowledge of the condition.

All other demographic variables were not significant.

5.2.1 Descriptive Information on Family Demographic and Cultural Factors

The majority of mothers (asthma, 76.67%; leukaemia, 91.30%; nephrotic syndrome, 90.91; control, 90%) were married. This indicates that many families are still two-parent families with a resident father (84% families of chronically ill and 86.67% control), and would suggest a greater reservoir of emotional support for the child. While there may be a high rate of divorce among Indians in South Africa and an increase in single-parent families in the Indian community over recent years, the percentage of such families is still low when compared with families in other countries, particularly Western countries such as the United States (Mahabeer 1989).

Most of the children (leukaemia, 73.91% nephrotic syndrome, 72.73%; control, 60.%) lived in nuclear rather than extended families. This finding is consistent with recent research on Indian families (Mahabeer 1989). There are many reasons for the change in family structure over the past few decades. These may include the influence of urbanisation in South Africa, apartheid policies (for example, relocation to smaller homes), politics, and Western ideology and education which has

led to changing attitudes to marriage and the family (Jithoo 1975, Schoombee and Manzaris 1984, Amod and Shmukler 1986, Pillay 1987). A relatively small percentage of asthmatic children live in nuclear families (43.33%) compared to those who live in extended families. This may have certain ramifications when one considers the stress patterns of the families of asthmatic children.

Most families belonged to the Hindu religion (asthma, 60%; leukaemia, 69.57%; nephrotic syndrome, 50%; control, 76.67%). This is in congruence with the population statistics for Indians in South Africa, where Hindus constitute approximately 70% of the Indian population (Central Statistical Services 1987).

Many families, including those belonging to the Moslem and Christian faith, sought assistance from a priest, particularly in times of difficulty (asthma, 60%; leukaemic, 78.26%; nephrotic syndrome, 54.55%). The cultural and religious practices of the total Indian sample may have contributed to a high percentage of families having "conducted prayers" to assist them with their ill children (asthma, 76.67%; leukaemia, 91.30%; nephrotic syndrome, 81.82%). The control group was equally religious, with approximately 70% having also "conducted prayers" to "assist" their children.

Many mothers were not employed outside the home (asthma, 73.33%; leukaemia, 78.26%; nephrotic syndrome, 90.91%; control, 80%). This trend could be explained in terms of the needs of a nuclear family which has younger children. It is likely that with the breakaway from the traditional extended family (Pillay 1989), many mothers would need to stay at home to care for their young, particularly if the child was seriously ill. While the role of Indian women may have changed from that of "home-maker and mother" (Ramasar 1966) to "working" or "career person" (Amod and Shmukler 1986), many

mothers still appear to maintain the role of "housewife."

Mothers in the chronically ill (62.16%) and control (58.62%) groups indicated that illness would bring them closer to their spouse rather than cause marital difficulties. However, conflicting evidence for increased marital distress in parents with a chronically ill child (Spaulding and Morgan 1986, Kazak et al. 1988, Walker et al. 1992). It may, therefore, be more appropriate to consider this factor relative to the problems that may present in individual families rather than a result of the illness.

A very small percentage in each group believed that illness was a punishment by God, or blamed themselves for the illness, a surprising finding in an otherwise religious community. This is consistent with findings of Peterman and Bode (1986) where 10 per cent of German families perceived cancer in their children to be a punishment.

The finding in the study that school absenteeism was not higher among chronically ill children (compared to children in the control group) is contrary to other research which indicates a high absenteeism rate among asthmatic and leukaemic children (Creer and Youches 1971, Hill et al. 1979, Lansky et al. 1983). This may be related to the definition of absenteeism, which may differ across studies. The present finding may be due to the perception of the mother which has not been confirmed by additional reports, for example from the teacher. A contributing factor may also be the influence of health professionals treating children with leukaemia and nephrotic syndrome. Parents of children with leukaemia have admitted to accepting the doctor's advice and not keeping their children away from school unnecessarily. Parents of children with nephrotic syndrome also reported a similar adherence to the doctor's suggestion.

5.3 A Comparison of the Families of Asthmatic, Leukaemic, Nephrotic Syndrome and Control Children

5.3.1 A Comparison of Parental Age

Table 6 : Means and standard deviations of scores according to mother's age

Group	N	Mean	SD
Control	30	33.6	5.171
Asthma	30	37.5	7.627
Leukaemia	23	33.6	6.243
Nephrotic	22	35.5	5.215

Table 7 : Means and standard deviations of scores according to father's age

Group	N	Mean	SD
Control	30	36.5	9.196
Asthma	30	33.5	17.063
Leukaemia	23	37.6	7.150
Nephrotic	22	37.8	9.701

Analyses of variance were computed to test for significant differences in the ages of the mothers and the fathers.

Table 8 : Analysis of variance of scores of mother's and father's ages

Variable	Sum of Squares	Mean Square	Mean	DF	F Value	p Value
Mother's age	291.2702	97.0900	35.200	3	2.49	0.0646
Father's age	336.7538	112.2512	36.295	3	0.80	0.4952

The F-statistic was not significant. However, the post hoc test for multiple comparisons revealed that the mothers of asthmatic children were marginally older than the mothers of leukaemic children and the control group of non chronically ill children. No significant differences were found for father's age across groups.

Table 8.1 : Results of Duncan's multiple range test : mother's age

Group	N	Mean	Duncaan Grouping
Asthma	30	37.567	A
Nephrotic Syndrome	22	35.591	A B
Control	30	33.767	B
Leukaemia	23	33.609	B

5.3.2 A Comparison of the Level of Income

An analysis of variance was computed and revealed a significant difference in the income across the four groups.

Table 9 : Analysis of variance of scores of level of income

Sum of Squares	Mean Square	Mean	DF	F Value	P Value
17966440.3	5988813.46	1412.09	3	4.36	.0062**

** $p < 0.01$

Duncan's multiple range test showed (see Table 9.1) that the families of children with nephrotic syndrome had significantly higher incomes than the families of asthmatic and control children ($p < 0.05$). Also, the families of leukaemic children had significantly higher incomes than the families of asthmatic and control children ($p < 0.05$).

Table 9.1 : Results of Duncan's multiple range test of level of income

Group	N	Mean	Duncan Grouping
Nephrotic Syndrome	22	1902.3	A
Leukaemia	23	1859.6	A
Control	30	1166.7	B
Asthma	30	955.0	B

5.3.3 Life Events and Changes among the Four Groups of Families

Analyses of variance were used to compare the groups on the different dimensions measured by the Family Life Events and Changes Scale (FILE). No significant differences were noted.

Tables 10 and 11 reflect scores for the four groups.

Table 10 : Means and standard deviations of FILE scores of asthmatic and control families

Group	Asthma		Control	
N	30		30	
Variable	Mean	SD	Mean	SD
Intr Fam	3.7666	2.635	2.9375	2.395
Marit Str	0.3333	0.884	0.2812	0.771
Preg Str	0.0666	0.253	0.1250	0.336
Fin Str	2.5666	1.546	2.1875	1.255
Ill Fam	1.2666	1.484	0.9375	1.075
Losses	0.7666	0.935	0.5000	0.567
Trans	0.3333	0.711	0.2500	0.508
Leg Vio	0.1333	0.434	0.0312	0.176
Work Fam	1.7000	1.622	1.3437	1.334

Table 11 : Means and standard deviations of FILE scores of leukaemic and nephrotic syndrome families

Group	Leukaemia		Nephrotic	
N	23		22	
Variable	Mean	SD	Mean	SD
Intr Fam	3.0869	2.447	2.8636	2.1667
Marit Str	0.3043	0.634	0.1818	0.5010
Preg Str	0.0869	0.288	-	-
Fin Str	2.1739	1.302	2.0000	2.1157
III Fam	0.7391	0.915	0.9545	0.9989
Losses	0.6086	0.891	0.3181	0.4767
Trans	0.4782	0.947	0.3636	0.8477
Leg Vio	0.0869	0.288	0.0454	0.2132
Work Fam	1.3913	1.305	1.2272	1.2317

As noted, there were no statistically significant differences among the four groups in respect of family life changes and events. Hypothesis 1 is, therefore, not supported.

5.3.4 Stress and Resources among the Four Groups of Families

Analyses of variance were computed to test for significant differences among the four groups on stress and resources, as measured by the QRS.

Table 12 : Means and standard deviations of QRS scores of four groups of families

Group	Asthma		Leukaemia		Nephrotic		Control		F	P
N	30		23		22		30			
Scale	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Value	Value
Sc1	5.466	3.30	3.956	2.78	4.454	2.85	3.233	2.51	3.12	0.0293*
Sc2	7.300	2.69	6.000	2.29	6.590	2.64	4.766	2.06	5.75	0.0011**
Sc3	9.133	3.74	8.217	2.99	8.272	4.16	7.400	2.88	1.25	0.2942
Sc4	6.233	2.38	4.391	1.92	4.590	2.44	4.733	2.33	3.79	0.0127*
Sc5	2.500	1.50	2.391	1.41	2.272	1.83	1.900	1.18	0.92	0.4339
Sc6	4.900	1.39	4.608	1.55	4.818	1.36	4.333	1.64	0.82	0.4871
Sc7	2.833	2.47	2.589	2.02	2.318	1.64	2.633	1.56	0.38	0.7676
Sc8	4.066	2.69	4.0000	2.61	3.181	1.65	2.733	2.08	2.18	0.0946
Sc9	2.366	1.99	1.956	1.79	1.818	1.99	1.266	1.33	1.94	0.1279
Sc10	7.333	3.94	5.217	4.08	4.954	3.22	4.933	2.65	3.12	0.0292*
Sc11	3.266	1.55	3.217	1.38	2.727	1.80	2.333	1.47	2.77	0.0454*
Sc12	2.000	1.17	1.826	1.40	1.500	1.22	1.633	1.18	0.82	0.4861
Sc13	1.833	1.41	2.043	1.33	2.227	1.54	1.500	1.04	1.44	0.2350
Sc14	1.200	0.96	1.304	1.06	1.454	1.10	0.966	0.92	1.09	0.3577
Sc15	7.233	4.18	7.217	3.94	5.818	2.82	5.566	3.00	1.69	0.1740

* $p < 0.05$

** $p < 0.01$

The above table indicates significant differences on scales 1, 2, 4, 10, and 11. To isolate these differences, Duncan's multiple range tests were computed for each of the 5 scale scores.

Table 12.1 : Results of Duncan's multiple range test : Poor Mood and Health (scale 1)

Group	N	Mean	Duncan Grouping
Asthma	30	5.467	A
Nephrotic Syndrome	22	4.455	A B
Leukaemia	23	3.957	A B
Control	30	3.233	B

Families of asthmatic children scored significantly higher than the families in the control group on the dimension of poor health/mood ($p < 0.05$).

Table 12.2 : Results of Duncan's multiple range test : Excess time demands (scale 2)

Group	N	Mean	Duncan Grouping
Asthma	30	7.300	A
Nephrotic Syndrome	22	6.591	A
Leukaemia	23	6.000	A B
Control	30	4.767	B

Families of asthmatic and nephrotic children scored significantly higher than the families in the control group on scale 2, that is, excess time demands ($p < 0.05$).

Table 12.3 : Results of Duncan's multiple range test : Negative attitude toward index case (scale 3)

Group	N	Mean	Duncan Grouping
Asthma	30	9.133	A
Nephrotic Syndrome	22	8.273	A
Leukaemia	23	8.217	A
Control	30	7.400	A

There were no significant differences among the four groups on scale 3, which represents negative attitude toward index case.

Table 12.4 : Results of Duncan's multiple range test : Over protection/dependency (scale 4)

Group	N	Mean	Duncan Grouping
Asthma	30	6.233	A
Nephrotic Syndrome	22	4.733	B
Leukaemia	23	4.591	B
Control	30	4.391	B

As observed, the families of asthmatic children scored significantly higher than the families in the nephrotic syndrome, leukaemic and control groups on scale 4, that is, overprotection/dependency ($p < 0.05$).

Table 12.5 : Results of Duncan's multiple range test : Financial problems (scale 10)

Group	N	Mean	Duncan Grouping
Asthma	30	7.333	A
Nephrotic Syndrome	22	5.217	B
Leukaemia	23	4.955	B
Control	30	4.933	B

Families of asthmatic children scored significantly higher than the families of leukaemic, nephrotic syndrome and control children on scale 10, representing financial problems ($p < 0.05$).

The post-hoc test was used to determine significant differences between the responses of four groups to physical incapacitation (scale 11).

Table 12.6 : Results of Duncan's multiple range test : Physical incapacitation (scale 11)

Group	N	Mean	Duncan Grouping
Asthma	30	3.267	A
Nephrotic Syndrome	22	3.217	A
Leukaemia	23	2.727	A
Control	30	2.233	B

The families of asthmatic, leukaemic and nephrotic syndrome children scored significantly higher than the families in the control group on scale 11, that is, physical incapacitation ($p < 0.05$).

Hypothesis 2, is therefore, supported.

5.3.5 Resources for Management among the Four Groups of Families

Analyses of variance were computed to test for significant differences among the four groups of families on their resources for management. A significant difference was noted on this variable.

Hypothesis 3 is, therefore, supported.

Table 13 : Analysis of variance of the Total Firm Scale scores of four groups of families

Resources for Management	Sum of Squares	DF	Mean	F Value	P Value
Total Scale	4230.8848	3	1410.2949	2.62	0.0549*

* $p < 0.05$

The table below shows that Duncan's multiple range test identified a significant difference between the nephrotic syndrome and asthmatic groups, and between the leukaemic and asthmatic group on the total FIRM scale. The families of nephrotic syndrome and leukaemic children scored significantly higher than the families of asthmatic children on this measure ($p < 0.05$).

Table 13.1 : Results of the Duncan's multiple range test of the four groups of families functioning on the Total FIRM Scale

Group	N	Mean	Duncan Grouping
Nephrotic Syndrome	22	117.727	A
Leukaemia	23	115.870	A
Control	30	107.967	A B
Asthma	30	101.833	B

The analysis of variance was also computed to test for significant differences across the four groups in their responses to the different dimensions of family resources for management, as measured by FIRM. Significant differences were found on the family strength I: esteem and communication (FS I) and financial well-being (FWB) dimensions.

Table 14 : Means and standard deviations of FIRM scores of four groups of families

Group Resources	Asthma		Leukaemia		Nephrotic		Control		F	P
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Value	Value
FSI	31.366	7.44	35.652	7.46	36.500	5.85	33.033	3.78	3.78	0.0145*
FSII	37.000	10.70	37.347	12.81	37.090	10.27	38.200	7.55	0.08	0.9702
EFSS	8.166	2.46	8.695	2.28	9.363	2.42	8.8000	2.46	1.05	0.3722
FWB	19.833	9.88	29.739	10.17	30.227	10.80	23.400	10.22	6.33	0.0006***
SFS	3.900	1.68	4.739	1.00	4.454	0.91	4.3330	0.84	2.29	0.0831
SD	13.633	3.40	13.130	3.38	13.909	2.74	13.333	3.12	0.27	0.848

* $p < 0.05$
*** $p < 0.001$

Duncan's multiple range test was used to isolate significant differences among the four groups on the resource dimensions of Family strength I: esteem and communication (FS I) and Financial well-being (FWB).

Table 14.1 : Results of the Duncan's multiple range test : Family strength I: esteem and communication

Group	N	Mean	Duncan Grouping
Nephrotic Syndrome	22	36.500	A
Leukaemia	23	35.652	A
Control	30	33.033	A B
Asthma	30	31.367	B

The families of nephrotic syndrome and leukaemic children scored significantly higher than the families of asthmatic children on the family resource of esteem and communication ($p < 0.05$).

Table 14.2 : Results of Duncan's multiple range test : Financial well-being

Group	N	Mean	Duncan Grouping
Nephrotic Syndrome	22	30.227	A
Leukaemia	23	29.739	A
Control	30	23.400	B
Asthma	30	19.833	B

The families of nephrotic syndrome and leukaemic children scored significantly higher than the families of asthmatic and control children on the financial well-being family scale ($p < 0.05$).

Hypothesis 3a is, therefore, supported.

5.3.6 Health-Related Coping Patterns among the Four Groups of Families

Analyses of variance were computed to test for significant differences across the four groups in their responses to

health-related coping patterns, as measured by the CHIP. Significant differences were found on coping pattern I and coping pattern III.

Table 15 : Means and standard deviations of CHIP scores of four groups of families

Coping N	Asthma 30		Leukaemia 23		Nephrotic 22		Control 30		F	P
Pattern	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Value	Value
CP I	43.333	7.44	47.913	6.20	49.500	7.14	45.766	7.44	3.66	0.0150*
CP II	27.100	7.97	29.304	8.33	33.136	10.24	30.566	8.47	2.14	0.1000
CP III	17.000	4.11	19.739	3.54	19.272	4.67	16.633	3.54	4.05	0.0092**

* $p < 0.05$

** $p < 0.01$

Duncan's multiple range test was used to isolate the significant differences between the four groups on Coping Pattern I (family integration, co-operation and an optimistic definition of the situation) and Coping Pattern III (understanding the health care situation through communication with other parents and consultation with the health care team).

Table 15.1 : Results of Duncan's multiple range test : Coping Pattern I

Group	N	Mean	Duncan Grouping
Nephrotic Syndrome	22	49.500	A
Leukaemia	23	47.913	A
Control	30	45.767	B A
Asthma	30	43.333	B

The families of nephrotic syndrome and leukaemic children scored significantly higher than the families of asthmatic children on coping pattern I, which is family integration, co-operation and an optimistic definition of the situation ($p < 0.05$).

Table 15.2 : Results of Duncan's multiple range test : Coping Pattern III

Group	N	Mean	Duncan Grouping
Nephrotic Syndrome	22	19.273	A
Leukaemia	23	19.739	A
Control	30	16.633	B
Asthma	30	17.000	B

As noted, families of leukaemic children scored significantly higher than families of asthmatic and control children on coping pattern III.The families of nephrotic syndrome children also scored significantly higher than the families of asthmatic and control children in their use of coping pattern III ($p < 0.05$).

Hypothesis 4 is, therefore, supported.

5.3.7 Family Crisis-Oriented Coping Strategies among the Four Groups of Families

Analyses of variance were computed to test for significant differences across the four groups' responses to family crisis-oriented personal evaluation coping (F-COPES). As evident in Table 16, a significant difference was noted.

Table 16 : Means and standard deviations of F-COPES scores of four groups of families

Group	Asthma		Leukaemia		Nephrotic		Control		F	P
N	30		23		22		30			
Coping Pattern	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Value	Value
ASS	26.933	8.84	28.304	7.54	31.181	9.49	28.266	6.82	1.17	0.3262
R	31.333	5.59	32.130	4.65	33.590	5.17	31.966	4.97	0.84	0.4738
SSS	14.266	4.12	15.608	3.93	17.681	2.67	14.800	4.57	3.48	0.0186*
MFAAH	12.033	3.34	12.391	4.29	13.636	4.03	11.733	2.53	1.36	0.2590
PA	6.733	1.48	7.086	1.80	7.090	2.58	7.000	1.68	0.22	0.8823

* $p < 0.05$

Table 16.1 displays the results of Duncan's multiple range test which was used to isolate the significant difference among the four groups on the "seeking spiritual support" coping strategy (SSS).

Table 16.1 : Results of Duncan's multiple range test : Seeking spiritual support

Group	N	Mean	Duncan Grouping
Nephrotic Syndrome	22	17.682	A
Leukaemia	23	15.609	A B
Control	30	14.800	B
Asthma	30	14.267	B

The families of nephrotic syndrome children scored significantly higher than families of the control and asthmatic children on the "seeking spiritual support" coping strategy (SSS) ($p < 0.05$). There were no significant differences among the groups on the other four coping strategies.

Hypothesis 5 is, therefore, supported.

5.4 Illness-Specific and Control Group Data

5.4.1. Family Life Events and Changes

5.4.1.1 Asthmatic and Control Groups

To investigate differences in family life events between families in the asthmatic and control groups, Student's t-tests were computed. No significant differences were found between the two groups on the measure of life events. Hypothesis 1a, is therefore, not supported.

Table 17 : Means and standard deviations of FILE scores of asthmatic and control families

	Asthma		Control		
N	30		30		
File	Mean	SD	Mean	SD	P Value
Total scale	10.9666	5.580	8.5666	4.643	0.0754

5.4.1.2 Leukaemic and Control Groups

Student's t-tests were computed to investigate the differences in family life events and changes between families in the leukaemic and control groups.

Table 18 : Means and standard deviations of FILE scores of leukaemic and control families

	Leukaemia		Control		
N	23		30		
File	Mean	SD	Mean	SD	P Value
Total scale	9.5217	5.566	8.5666	4.643	0.4991

No significant differences were noted. Hypothesis 1a is, therefore, not supported.

5.4.1.3 Nephrotic Syndrome and Control Groups

The t-test procedure was computed to examine differences between the families in the nephrotic syndrome and control groups on family life events and changes.

Table 19 : Means and standard deviations of FILE scores of nephrotic syndrome and control families

	Nephrotic Syn		Control		
N	22		30		
File	Mean	SD	Mean	SD	P Value
Total scale	7.9545	4.990	8.5666	4.643	0.6550

No significant differences were observed. Hypothesis 1a is, therefore, not supported

5.4.2 Stress and Resources

5.4.2.1 Asthmatic and Control Groups

To investigate the differences in stress and resources between the families in the asthmatic and control groups, t-tests were computed.

Table 20 : Means and standard deviations of QRS scores of asthmatic and control families

N		Asthma 30		Control 30		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	5.4666	3.308	3.2333	2.514	0.0047**
2	Excess time demands	7.3000	2.692	4.7666	2.062	0.0001***
3	Negative attitude toward index case	9.1333	3.748	7.4000	2.883	0.0494*
4	Overprotection/dependency	6.2333	2.387	4.7333	2.333	0.0169*
5	Lack of social support	2.5000	1.502	1.9000	1.184	0.0913
6	Overcommitment/martyrdom	4.9000	1.398	4.3333	1.647	0.1562
7	Pessimism	2.8333	2.478	2.6333	1.564	0.7100
8	Lack of family integration	4.0666	2.690	2.7333	2.083	0.0360*
9	Limits of family opportunity	2.3666	1.991	1.2666	1.337	0.0148*
10	Financial problems	7.3333	3.942	4.9333	2.651	0.0076**
11	Physical incapacitation	3.2666	1.552	2.2333	1.478	0.0106*
12	Lack of activities for index case	2.0000	1.174	1.6333	1.188	0.2343
13	Occupational limitation	1.8330	1.416	1.5000	1.042	0.3034
14	Social obtrusiveness	1.2000	0.961	0.9666	0.927	0.8500
15	Difficult personality characteristics	7.2333	4.182	5.5666	3.002	0.0815

* $p < 0.05$
** $p < 0.01$
*** $p < 0.001$

Significant differences were found between the families in the asthmatic and control groups on poor health/mood, excess time demands, negative attitude toward index case, overprotection/dependency, lack of family integration, limits

on family opportunity, financial problems, and physical incapacitation. The families in the asthmatic group scored significantly higher on all these dimensions. Hypothesis 2a is, therefore, supported.

5.4.2.2 Leukaemic and Control Groups

Student's t-tests were computed to determine the differences in stress and resources between the families in the leukaemic and control groups.

Table 21 : Means and standard deviations of QRS scores of leukaemic and control families

N		Leukaemia 23		Control 30		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	3.9565	2.787	3.2333	2.514	0.3269
2	Excess time demands	6.0000	2.296	4.7666	2.062	0.0451*
3	Negative attitude toward index case	8.2173	2.999	7.4000	2.883	0.3196
4	Overprotection/dependency	4.3913	1.924	4.7333	2.333	0.5714
5	Lack of social support	2.3913	1.405	1.9000	1.184	0.1737
6	Overcommitment/martyrdom	4.6086	1.559	4.3333	1.647	0.5398
7	Pessimism	2.8695	2.029	2.6333	1.564	0.6341
8	Lack of family integration	4.0000	2.611	2.7333	2.083	0.0549
9	Limits of family opportunity	1.9565	1.795	1.2666	1.337	0.1149
10	Financial problems	5.2173	4.089	4.9333	2.651	0.7608
11	Physical incapacitation	3.2173	1.380	2.2333	1.478	0.0168*
12	Lack of activities for index case	1.8260	1.402	1.6333	1.188	0.5908
13	Occupational limitation	2.0434	1.330	1.5000	1.042	0.1014
14	Social obtrusiveness	1.3043	1.063	0.9666	0.927	0.2234
15	Difficult personality characteristics	7.2173	3.942	5.5666	3.002	0.0894

* $p < 0.05$

Significant differences were found between the families in the leukaemic and control groups on excess time demands and physical incapacitation. The families in the leukaemic group scored significantly higher on these two dimensions. These

results support hypothesis 2a.

5.4.2.3 Nephrotic Syndrome and Control Groups

The t-test was also used to investigate the differences in stress and resources between families in the nephrotic syndrome and control groups.

Table 22 : Means and standard deviations of QRS scores of nephrotic syndrome and control families

N		Nephrotic Syndrome 22		Control 30		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	4.4545	2.857	3.2333	2.514	0.1087
2	Excess time demands	6.5909	2.648	4.7666	2.062	0.0074**
3	Negative attitude toward index case	8.2727	4.165	7.4000	2.883	0.3759
4	Overprotection/dependency	4.5909	2.442	4.7333	2.333	0.8320
5	Lack of social support	2.2727	1.830	1.9000	1.184	0.3772
6	Overcommitment/martyrdom	4.8181	1.367	4.3333	1.647	0.2661
7	Pessimism	2.3181	1.644	2.6333	1.564	0.4857
8	Lack of family integration	3.1818	1.651	2.7333	2.083	0.4078
9	Limits of family opportunity	1.8181	1.991	1.2666	1.337	0.2377
10	Financial problems	4.9545	3.228	4.9333	2.651	0.9794
11	Physical incapacitation	2.7272	1.804	2.2333	1.478	0.2835
12	Lack of activities for index case	1.5000	1.224	1.6333	1.188	0.6948
13	Occupational limitation	2.2272	1.540	1.5000	1.042	0.0476*
14	Social obtrusiveness	1.4545	1.100	0.9666	0.927	0.0896
15	Difficult personality characteristics	5.8181	2.822	5.5666	3.002	0.7608

* $p < 0.05$

** $p < 0.01$

Table 22 indicates that significant differences were found between the families in the nephrotic syndrome and control groups on excess time demands and occupational limitations. The results indicate that families in the nephrotic group scored significantly higher in these areas. These results support hypothesis 2a.

5.4.3 Resources for Management

To investigate the differences in resources for management between families in the asthmatic and control, leukaemic and control, and nephrotic syndrome and control groups, Student's t-tests were computed.

5.4.3.1 Asthmatic and Control Groups

As depicted in Table 23, the results revealed that there were no significant differences between the families in the asthmatic and control groups in their resources for management. Hypothesis 3a is, therefore, not supported.

Table 23 : Means and standard deviations of FIRM scores of asthmatic and control families

N	Asthma 30		Control 30		
Resource	Mean	SD	Mean	SD	P Value
FS I	31.3666	7.448	33.0333	3.782	0.2790
FS II	37.0000	10.706	38.2000	7.553	0.6178
EFSS	8.1666	2.464	8.8000	2.469	0.3242
FWB	19.8333	9.889	23.4000	10.223	0.1749
SFS	3.9000	1.688	4.3333	0.844	0.2137
SD	13.6333	3.408	13.3333	3.122	0.7235

5.4.3.2 Leukaemic and Control Groups

To investigate the differences in resources between the families in the leukaemic and control groups, t-tests were computed.

Table 24 : Means and standard deviations of FIRM scores of leukaemic and control families

N	Leukaemia 23		Control 30		
Resource	Mean	SD	Mean	SD	P Value
FS I	35.6521	7.468	33.033	3.782	0.1020
FS II	37.3478	12.819	38.200	7.553	0.7635
EFSS	8.6956	2.285	8.800	2.469	0.8755
FWB	29.7391	10.176	23.400	10.223	0.0294*
SFS	4.7391	1.009	4.333	0.844	0.1174
SD	13.1130	3.388	13.333	3.122	0.8221

* $p < 0.05$

The results reveal that the families in the leukaemic group scored significantly higher than the families in the control group on the financial well-being scale (FWB). Hypothesis 3a is, therefore, supported.

5.4.3.3 Nephrotic Syndrome and Control Groups

The Students's t-test was computed to investigate possible differences between the families in the nephrotic syndrome and control groups on the management of their resources.

Table 25 : Means and standard deviations of FIRM scores of nephrotic syndrome and control families

	Nephrotic Syndrome		Control		
N	22		30		
Resource	Mean	SD	Mean	SD	P Value
FS I	36.5000	5.853	33.0333	3.782	0.0125*
FS II	37.0909	10.299	38.2000	7.553	0.6558
EFSS	9.3636	2.421	8.8000	2.469	0.4162
FWB	30.2272	10.800	23.4000	10.223	0.0243*
SFS	4.4545	0.911	4.3333	0.844	0.6231
SD	13.9090	2.741	13.3333	3.122	0.4927

* $p < 0.05$

The results reveal that the families in the nephrotic syndrome group scored significantly higher than the families in the control group in their management of the following resources: family strength I: esteem and communication (FS I) and financial well-being (FWB). Hypothesis 3a is, therefore, supported.

5.4.4 Health-Related Coping Patterns

5.4.4.1 Asthmatic and Control Groups

To investigate the differences in coping patterns between the families in the asthmatic and control groups, t-tests were computed.

Table 26 : Means and standard deviations of CHIP scores of asthmatic and control families

N	Asthma 30		Control 30		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	43.3333	7.443	45.7666	7.440	0.2104
CP II	27.1000	7.979	30.5666	8.479	0.1084
CP III	17.0000	4.110	16.6333	3.547	0.7128

There were no significant differences in the coping patterns of families in the asthmatic and control groups. Hypothesis 4a is, therefore, not supported.

5.4.4.2 Leukaemic and Control Groups

Student's t-tests were computed to determine the difference in coping patterns between families in the leukaemic and control groups.

Table 27 : Means and standard deviations of CHIP scores of leukaemic and control families

N	Leukaemia 23		Control 30		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	47.9130	6.207	45.7666	7.440	0.2694
CP II	29.3043	8.330	30.5666	8.479	0.5907
CP III	19.7391	3.544	16.6333	3.547	0.0027*

* $p < 0.05$

The results reveal that the families in the leukaemic group scored significantly higher than the families in the control group on coping pattern III, that is, understanding the health care situation through communication with other parents and consultation with the health care team. Thus, hypothesis 4a is supported.

5.4.4.3 Nephrotic Syndrome and Control Groups

The results of the t-test used to investigate differences, if any, in coping patterns between families in the nephrotic syndrome and control groups are displayed in Table 28.

Table 28 : Means and standard deviations of CHIP scores of nephrotic syndrome and control families

	Nephrotic Syndrome		Control		
N	22		30		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	49.5000	7.143	45.7666	7.440	0.0751
CP II	33.1363	10.241	30.5666	8.479	0.3278
CP III	19.2727	4.671	16.6333	3.547	0.0246*

* $p < 0.05$

Families in the nephrotic syndrome group scored significantly higher than families in the control group on coping pattern III. Hypothesis 4a is, therefore, supported.

5.4.5 Family Crisis-Oriented Coping Strategies

5.4.5.1 Asthmatic and Control Groups

To investigate the differences in family crisis-oriented coping strategies between families in the asthmatic and control groups, the t-test was computed.

Table 29 : Means and standard deviations of F-COPES scores of asthmatic and control families

	Asthma		Control		
N	30		30		
Coping Strategy	Mean	SD	Mean	SD	P Value
ASS	26.9333	8.847	28.2666	6.822	0.5159
R	31.3333	5.597	31.9666	4.972	0.6449
SSS	14.2666	4.126	14.8000	4.574	0.6372
MFAAH	12.0333	3.347	11.7333	2.531	0.6969
PA	6.7333	1.484	7.0000	1.681	0.5175

There were no significant differences in the family crisis-oriented coping strategies between the two groups of families. Hypothesis 5a is, therefore, not supported.

5.4.5.2 Leukaemic and Control Groups

As depicted below, there were no significant differences in the use of family crisis oriented coping strategies between families in the leukaemic and control groups. Hypothesis 5a is, therefore, not supported.

Table 30 : Means and standard deviations of F-COPES scores of leukaemic and control families

	Leukaemia		Control		
N	23		30		
Coping Strategy	Mean	SD	Mean	SD	P Value
ASS	28.3043	7.540	28.2666	6.822	0.9849
R	32.1304	4.654	31.9666	4.972	0.9033
SSS	15.6086	3.939	14.8000	4.574	0.5017
MFAAH	12.3913	4.293	11.7333	2.531	0.4888
PA	7.0869	1.806	7.0000	1.681	0.8574

5.4.5.3 Nephrotic Syndrome and Control Groups

The t-tests were used to investigate differences in family crisis-oriented coping strategies between families in the nephrotic syndrome and control groups.

Table 31 : Means and standard deviations of F-COPES scores nephrotic syndrome and control families

	Nephrotic Syndrome		Control		
N	22		30		
Coping Strategy	Mean	SD	Mean	SD	P Value
ASS	31.1818	9.490	28.2666	6.822	0.2030
R	33.5909	5.179	31.9666	4.972	0.2583
SSS	17.6818	2.679	14.8000	4.574	0.0111*
MFAAH	13.6363	4.030	11.7333	2.531	0.0419*
PA	7.0909	2.580	7.0000	1.681	0.8784

* $p < 0.05$

Table 31 indicates that families in the nephrotic syndrome group scored significantly higher than families in the control group on the family crisis-oriented coping strategies of "seeking spiritual support" (SSS) and "mobilising family to acquire and accept help" (MFAAH). Hypothesis 5a is, therefore, supported.

5.5 Chronically Ill and Control Families

The three chronic illness groups - namely asthma, leukaemia and nephrotic syndrome - were collapsed into a single chronic illness group for the purpose of certain computations, the results of which are displayed below.

5.5.1 Descriptive Statistics on Family and Cultural Variables

Chi-square analyses were computed to compare the chronically ill and the control groups on family demographic and cultural variables.

Table 32 : Distribution of chronically ill and control samples according to demographic and cultural variables

N	Chronic illness 75		Control 30		
Variable	Frequency	Percentage	Frequency	Percentage	P Value
MARITAL STATUS					NS
single	2	2.67	2	06.67	
married	64	85.33	27	90.00	
divorced	5	6.67	0	00.00	
widowed	4	5.33	1	03.33	
RELIGION					NS
christian	14	18.67	6	20.00	
hindu	45	60.00	23	76.67	
moslem	16	21.33	1	03.33	
MATERNAL OCCUPATION					NS
housewife	60	80.00	24	80.00	
skilled	6	8.00	4	13.33	
unskilled	4	5.33	0	00.00	
unemployed	5	6.67	2	06.67	
MOTHER'S EDUCATION					NS
0	1	1.33	0	00.00	
< std 3	3	4.00	0	00.00	
std 3-4	8	10.67	0	00.00	
std 5-6	3	4.00	1	0.33	
std 7-8	24	32.00	12	40.00	
std 9-10	17	22.67	14	46.67	
> 10	16	21.33	3	10.00	
degree	3	4.00	0	00.00	
FAMILY STATUS					NS
nucleur	46	61.33	18	60.00	
extended	29	38.67	12	40.00	
CULTURAL PRACTICES					NS
priest	48	64.00	12	40.00	0.025*
prayers	62	82.67	21	70.00	
God	24	32.00	5	16.67	
self-blame	16	21.33	6	20.00	
MARITAL PROBLEMS					NS
closer to spouse	46	62.16	17	58.62	
marital problems	11	14.86	2	6.90	
MEDICAL KNOWLEDGE	53	70.67	13	43.33	0.009**
SEVERITY OF CONDITION					
no symptoms	37	49.33	19	63.33	
symptoms					
PROGNOSIS					
normal expectancy	34	45.33	20	66.67	
progression of disease	41	54.67	10	33.33	0.048*

* $p < 0.05$

* * $p < 0.01$

5.5.1.1 Descriptive Information on Family and Cultural Factors

The largest percentage of mothers in both groups were married, were housewives, and belonged to the Hindu religion. Both groups lived predominantly in a nuclear family system. A large percentage of mothers in both groups had secondary school level of education with 46.67 per cent of the mothers in the control group having a Standard 9 or 10 level and 32 per cent of mothers in the chronically ill group having reached a Standard 7 or 8 level.

Significantly more families in the chronically ill group sought assistance from a priest (64%), had medical knowledge (70.67%), and indicated a poor prognosis of their childrens' condition (54.67%). As expected, many more mothers in the control group perceived their children as being healthy and free of physical symptoms (63.33%), with 66.67 per cent indicating a normal life expectancy for their children. Families of chronically ill children admitted to having more knowledge of their children's condition than the families of control children ($p < 0.01$).

5.5.2 Family Life Events and Changes between Chronically Ill and Control Families

The Student's t-tests were computed to examine differences in family life events and changes between the chronically ill and control groups.

Table 33 : Means and standard deviations of FILE scores of chronically ill and control families

	Chronic illness		Control		
N	75		30		
File	Mean	SD	Mean	SD	P Value
Total Scale	9.6400	5.481	8.5666	4.643	0.3470

No significant differences were noted. Hypothesis 6 is, therefore, not supported.

5.5.3 Stress and Resources between Chronically Ill and Control Families

Student t-tests were conducted to investigate the differences in the stress and resources between the chronically ill and control groups.

Table 34 : Means and standard deviations of QRS scores of chronically ill and control families

N		Chronic illness 75		Control 30		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	4.706	3.056	3.233	2.514	0.0212*
2	Excess time demands	6.693	2.588	4.766	2.062	0.0004***
3	Negative attitude toward index case	8.600	3.646	7.400	2.883	0.0796
4	Overprotection/dependency	5.186	2.403	4.733	2.333	0.3807
5	Lack of social support	2.400	1.559	1.900	1.184	0.0800
6	Overcommitment/martyrdom	4.786	1.426	4.333	1.647	0.1626
7	Pessimism	2.693	2.111	2.633	1.564	0.8883
8	Lack of family integration	3.786	2.406	2.733	2.083	0.0380*
9	Limits of family opportunity	2.080	1.922	1.266	1.337	0.0366*
10	Financial problems	5.986	3.905	4.933	2.651	0.1782
11	Physical incapacitation	3.093	1.578	2.233	1.478	0.0117*
12	Lack of activities for index case	1.800	1.262	1.633	1.188	0.5360
13	Occupational limitation	2.013	1.418	1.500	1.042	0.0446*
14	Social obtrusiveness	1.306	1.026	0.966	0.927	0.1184
15	Difficult personality characteristics	6.813	3.762	5.566	3.002	0.0792

* $p < 0.05$

*** $p < 0.001$

The results indicate that the chronically ill group scored significantly higher than the control group on poor health/mood, excess time demands, lack of family integration, limits on family opportunity, physical incapacitation, and occupational limitation scales. Hypothesis 7 is, therefore, supported.

5.5.4 Resources for Management between Chronically Ill and Control Families

Student t-tests were conducted to investigate the differences in the resources for management between the chronically ill and control groups.

Table 35 : Means and standard deviations of FIRM scores of chronically ill and control families

	Chronic illness		Control		
N	30		30		
Resource	Mean	SD	Mean	SD	P Value
FS I	34.1866	7.316	33.0333	3.782	0.2932
FS II	37.1333	11.131	38.2000	7.553	0.5731
EFSS	8.6800	2.417	8.8000	2.469	0.8218
FWB	25.9200	11.282	23.4000	10.223	0.2728
SFS	4.3200	1.337	4.3333	0.844	0.9514
SD	13.5600	3.193	13.3333	3.122	0.7397

There were no significant differences in the resources for management between the chronically ill and control groups. Hypothesis 8 is, therefore, not supported.

5.5.5 Health-Related Coping Patterns between Chronically Ill and Control Families

Student t-tests were used to investigate the differences in health-related coping patterns between the chronically ill and control groups.

Table 36 : Means and standard deviations of CHIP scores of chronically ill and control families

	Chronic illness		Control		
N	75		30		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	46.5466	7.416	45.7666	7.440	0.6291
CP II	29.5466	9.034	30.5666	8.479	0.5870
CP III	18.5066	4.256	16.6333	3.547	0.0245*

* $p < 0.05$

The results indicate that the chronically ill group scored significantly higher than the control group in the utilisation of coping pattern III, thus supporting hypothesis 9.

5.5.6 Family Crisis Oriented Coping Strategies between Chronically Ill and Control Families

Student t-tests were conducted to investigate the differences in family crisis-oriented coping strategies between the chronically ill and control groups.

Table 37 : Means and standard deviations of F-COPES scores of chronically ill and control families

	Chronic illness		Control		
N	75		30		
Coping Strategy	Mean	SD	Mean	SD	P Value
ASS	28.6000	8.733	28.2666	6.822	0.8359
R	32.2400	5.216	31.9666	4.972	0.8028
SSS	15.6800	3.915	14.8000	4.574	0.3589
MFAAH	12.6133	3.865	11.7333	2.531	0.1746
PA	6.9466	1.937	7.0000	1.681	0.8888

As indicated in the table above, there were no significant differences between the chronically ill and control groups in their family crisis-oriented coping strategies. Hypothesis 10 is, therefore, not supported.

5.6 Phase of Illness

The leukaemia and nephrotic syndrome groups were further divided into two sub-groups, for the purpose of comparing subjects in remission with those in the induction phase. The results of the computations are displayed in Tables 38 to 43.

5.6.1 Demographic Information

Table 38 : Demographic information on illness sub-groups

Variable		Remission		Induction	
Group	Frequency	Percentage	Frequency	Percentage	P Value
LEUKAEMIA	11	50.00	12	52.17	
NEPHROTIC	11	50.00	11	47.83	0.088
SEX					
Female	11	50.00	6	26.09	
Male	11	50.00	17	73.91	0.098
NO OF ADMISSIONS					
0	20	90.91	16	69.57	NS
1	2	9.09	4	17.39	
2	0	0.00	2	8.70	
3	.	.	.	.	
4	0	0.00	1	4.35	

The results in Table 38 indicate that there were no significant differences between the two groups and gender of the children in the remission and induction sub-groups. The number of admissions for children in the remission and induction sub-groups were also not significantly different. There were more males than females in the induction sub-group (73.91%).

Table 39 : Means and standard deviations of scores of age of members in sub-groups

Phase : Remission				
Group	N	Mean	SD	P Value
child	22	10.00	0.1361	***
mother	22	36.50	4.6971	**
father	22	39.00	9.7247	
Phase : Induction				
Group	N	Mean	SD	P Value
child	23	8.80	0.1140	NS
mother	23	32.00	6.0478	NS
father	23	35.80	6.5475	NS

** $p < 0.01$

*** $p < 0.001$

Children in the remission sub-group were significantly older than those in the induction sub-group ($p < 0.001$). Mothers of children in the remission sub-group were also significantly older than mothers in the induction sub-group ($p < 0.01$).

5.6.2 Phase of Illness and Stress and Resources

The Students's t-tests were computed to investigate differences in stress and resources between the remission and induction groups.

Table 40 : Means and standard deviations of QRS scores of remission and induction sub-groups

N		Remission 22		Induction 23		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	3.909	2.524	4.478	3.072	0.5001
2	Excess time demands	5.363	1.813	7.173	2.707	0.0120*
3	Negative attitude toward index case	7.772	3.840	8.695	3.322	0.3928
4	Overprotection/dependency	4.136	2.166	4.826	2.166	0.2918
5	Lack of social support	2.454	1.503	2.217	1.730	0.6268
6	Overcommitment/martyrdom	4.772	1.631	4.652	1.300	0.7848
7	Pessimism	2.318	1.835	2.869	1.866	0.3235
8	Lack of family integration	3.363	1.787	3.826	2.569	0.4891
9	Limits of family opportunity	1.681	1.861	2.086	1.904	0.4747
10	Financial problems	4.909	3.938	5.260	3.440	0.7509
11	Physical incapacitation	2.363	1.093	3.565	1.804	0.0101*
12	Lack of activities for index case	1.590	1.259	1.739	1.388	0.7099
13	Occupational limitation	1.772	1.269	2.478	1.503	0.0970
14	Social obtrusiveness	1.272	1.077	1.478	1.081	0.5265
15	Difficult personality characteristics	5.636	3.288	7.391	3.499	0.0901

* $p < 0.05$

Table 40 indicates that the induction sub-group scored significantly higher than the remission sub-group on the "excess time demands" and "physical incapacitation" scales. Hypothesis 11 is, therefore, supported.

5.6.3 Phase of Illness and Resources for Management

Student's t-tests were computed to examine differences in the management of resources between the remission and induction sub-groups.

Table 41 : Means and standard deviations of FIRMS scores of remission and induction sub-groups

	Remission		Induction		
N	22		23		
Resource	Mean	SD	Mean	SD	P Value
FS I	37.5000	5.316	34.6956	7.606	0.1582
FS II	38.1363	10.575	36.3478	12.539	0.6085
EFSS	8.9090	2.428	9.1304	2.321	0.7564
FWB	30.8636	9.876	29.1304	10.972	0.5802
SFS	4.6363	0.953	4.5652	0.992	0.8074
SD	13.4090	3.150	13.1304	4.505	0.8323

There were no significant differences in the resources utilised by the remission and induction sub-groups. These results, therefore, do not support hypothesis 12.

5.6.4 Phase of Illness and Health-Related Coping Patterns

To investigate the differences in the use of coping patterns between the remission and induction sub-groups, Student's t-tests were computed. Table 42 indicates that there were no significant differences in the coping patterns utilised by families in induction and those in remission. Hypothesis 13 is, therefore, not supported.

Table 42 : Means and standard deviations of CHIP scores of remission and induction sub-groups

	Remission		Induction		
N	22		23		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	48.5000	7.781	48.8695	5.537	0.8559
CP II	32.2272	10.405	30.1739	8.456	0.7623
CP III	19.3181	4.581	19.6956	3.661	0.7623

5.6.5 Phase of Illness and Family Crisis-Oriented Coping Strategies

The results of the t-tests computed to investigate differences in family crisis-oriented coping strategies between the remission and induction sub-groups are indicated in Table 43.

Table 43 : Means and standard deviations of F-COPES scores of remission and induction sub-groups

	Remission		Induction		
N	22		23		
Coping Strategy	Mean	SD	Mean	SD	P Value
A	30.0909	8.825	29.3478	8.509	0.7753
R	32.3636	4.315	33.4043	5.489	0.5253
SSS	16.7272	3.326	16.5217	3.740	0.8463
MFAAH	12.8636	3.882	13.1304	4.505	0.8322
PA	7.2727	1.856	6.9130	2.502	0.5859

There were no significant differences between the induction and remission sub-groups in their utilisation of family crisis-oriented coping strategies. Hypothesis 13 is, therefore, not supported.

5.7 Gender and Stress and Resources

The Student t-tests were computed to examine differences in stress between families of boys and girls.

Table 44 : Means and standard deviations of QRS scores of families of girls and boys

N		Girls 48		Boys 57		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	3.4166	2.640	5.0175	3.067	0.0049**
2	Excess time demands	5.5625	2.323	6.6315	2.723	0.0323*
3	Negative attitude toward index case	7.7083	3.024	8.7192	3.778	0.1310
4	Overprotection/dependency	4.3750	2.366	5.6315	2.256	0.0067**
5	Lack of social support	2.0000	1.237	2.4736	1.626	0.0936
6	Overcommitment/martyrdom	4.4583	1.597	4.8245	1.403	0.2193
7	Pessimism	2.5833	1.660	2.7543	2.198	0.6511
8	Lack of family integration	3.2500	2.401	3.6842	2.323	0.3511
9	Limits of family opportunity	1.4791	1.398	2.1578	2.051	0.0548
10	Financial problems	5.5000	3.886	5.8421	3.390	0.6351
11	Physical incapacitation	2.5208	1.570	3.1228	1.570	0.0532
12	Lack of activities for index case	1.6458	1.157	1.8421	1.306	0.4164
13	Occupational limitation	1.7708	1.462	1.9573	1.230	0.5096
14	Social obtrusiveness	1.0625	0.885	1.3333	1.091	0.1633
15	Difficult personality characteristics	5.8125	3.219	7.0000	3.821	0.0870

* $p < 0.05$

** $p < 0.01$

Table 44 indicates that families of boys and girls experienced stress significantly differently. In respect of boys, families scored significantly higher on poor health/mood, excess time demands, and the overprotection/dependency scales. Marginal significance was observed on the scales of limits on family opportunity and physical incapacitation. Hypothesis 14 is, therefore, supported.

5.7.1 Gender and Resources for Management

The Student's t-tests were computed to assess resources for management in relation to gender.

Table 45 : Means and standards deviations of FIRM scores of families of girls and boys

	Girls		Boys		
N	48		57		
Resource	Mean	SD	Mean	SD	P Value
FS I	33.7083	5.867	33.9824	7.052	0.8283
FS II	38.2083	9.600	36.7894	10.743	0.4766
EFSS	8.7291	2.160	8.7017	2.638	0.9535
FWB	25.6666	10.796	24.8070	11.251	0.6910
SFS	13.3541	3.056	13.6140	3.266	0.6749
SD	4.2708	1.425	4.3684	1.011	0.6833

No significant differences were observed. Hypothesis 15 is, therefore, not supported.

5.7.2 Gender and Health-Related Coping Patterns

The Student's t-tests were computed to examine whether gender differences occurred in relation to coping patterns.

Table 46 : Means and standard deviations of CHIP scores of families of girls and boys

	Girls		Boys		
N	48		57		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	46.4375	7.336	46.2280	7.509	0.8857
CP II	17.5146	3.752	18.3333	4.437	0.3243
CP III	30.1250	8.273	29.5964	9.376	0.7597

No significant differences were noted. The results, therefore, do not support hypothesis 15.

5.7.3 Gender and Family Crisis-Oriented Coping Strategies

Student's t-tests compared the use of family crisis-oriented coping strategies in relation to boys and girls. A significant difference was noted, thereby supporting hypothesis 15.

Table 47 : Means and standard deviations of F-COPES scores of families of girls and boys

	Girls		Boys		
N	48		57		
Coping Strategy	Mean	SD	Mean	SD	P Value
ASS	29.0000	7.539	28.0877	8.765	0.5677
R	32.0833	5.177	32.2280	5.127	0.8863
SSS	15.1875	4.103	15.6315	4.243	0.5835
MFAAH	11.6458	2.999	12.9649	3.872	0.0521
PA	7.4583	1.901	6.5438	1.732	0.0122*

* $p < 0.05$

Subjects scored significantly higher on the passive appraisal coping strategy (PA) and marginally higher on the mobilising family to acquire and accept help coping strategy (MFAAH) in respect of girls.

5.8 Stressors associated with Resources and Coping Variables

Pearson correlation coefficients (r) were computed across all subjects, for each stress or count with each resource and coping dimension to determine the strength of the associations. Significant correlations are displayed below.

Stress Scale

QRS

N 105

Resources and Coping

FIRM :

FS I	sc	1	-0.3001**
	sc	2	-0.3424**
	sc	3	-0.0723
	sc	4	-0.2700
	sc	5	-0.0773
	sc	6	-0.2830
	sc	7	-0.1992
	sc	8	-0.3024**
	sc	9	-0.3730***
	sc	10	-0.4179***
	sc	11	-0.1858
	sc	12	-0.1797
	sc	13	-0.2661
	sc	14	-0.2390
	sc	15	-0.3451**
FS II	sc	1	-0.5760***
	sc	2	-0.3165**
	sc	3	-0.3139**
	sc	4	-0.2402
	sc	5	-0.2087
	sc	6	-0.4090***
	sc	7	-0.1884
	sc	8	-0.2197
	sc	9	-0.2943

	sc	10	-0.4193***
	sc	11	-0.1720
	sc	12	-0.2201
	sc	13	-0.2757
	sc	14	-0.0894
	sc	15	-0.2175
EFSS	sc	1	-0.0673
	sc	2	-0.0378
	sc	3	-0.0391
	sc	4	-0.0888
	sc	5	-0.1570
	sc	6	-0.1253
	sc	7	-0.1916
	sc	8	-0.2736
	sc	9	-0.1573
	sc	10	-0.2028
	sc	11	-0.0114
	sc	12	-0.0302
	sc	13	-0.3117**
	sc	14	-0.2316
	sc	15	-0.1827
FWB	sc	1	-0.4504***
	sc	2	-0.4538***
	sc	3	-0.2350
	sc	4	-0.3726***
	sc	5	-0.1774
	sc	6	-0.3421**
	sc	7	-0.1621
	sc	8	-0.2732
	sc	9	-0.4004***
	sc	10	-0.6907***
	sc	11	-0.1464
	sc	1	2-0.3293**
	sc	13	-0.2092
	sc	14	-0.0072
	sc	15	-0.3364**
SFS	sc	1	-0.2868
	sc	2	-0.3359**
	sc	3	-0.0883

	sc	4	-0.1829
	sc	5	-0.0470
	sc	6	-0.0811
	sc	7	-0.2018
	sc	8	-0.2404
	sc	9	-0.3765***
	sc	10	-0.5648***
	sc	11	-0.1186
	sc	12	-0.1829
	sc	13	-0.2101
	sc	14	-0.3248
	sc	15	-0.0652
SD	sc	1	-0.2462
	sc	2	-0.2341
	sc	3	-0.1877
	sc	4	-0.1737
	sc	5	-0.1163
	sc	6	-0.2155
	sc	7	-0.2203
	sc	8	-0.2829
	sc	9	-0.3437**
	sc	10	-0.3536**
	sc	11	-0.1377
	sc	12	-0.1452
	sc	13	-0.2594
	sc	14	-0.2143
	sc	15	-0.2497

CHIP :

CP I	sc	1	-0.2819
	sc	2	-0.2350
	sc	3	-0.1156
	sc	4	-0.2954
	sc	5	-0.0916
	sc	6	-0.2040
	sc	7	-0.1902
	sc	8	-0.4082***
	sc	9	-0.2905

	sc	1	0-0.4560***
	sc	11	-0.1637
	sc	12	-0.1419
	sc	13	-0.2130
	sc	14	-0.0293
	sc	15	-0.3194**
CPII	sc	1	-0.1936
	sc	2	-0.2215
	sc	3	-0.0086
	sc	4	-0.1421
	sc	5	-0.1066
	sc	6	-0.1195
	sc	7	-0.1684
	sc	8	-0.4477***
	sc	9	-0.2770
	sc	10	-0.4595***
	sc	11	-0.1637
	sc	12	-0.2017
	sc	13	-0.1884
	sc	14	-0.1056
	sc	15	-0.3431**
CP III	sc	1	-0.2205
	sc	2	-0.1454
	sc	3	-0.0008
	sc	4	-0.2443
	sc	5	-0.1393
	sc	6	-0.1365
	sc	7	-0.2078
	sc	8	-0.2976
	sc	9	-0.2039
	sc	10	-0.3947***
	sc	11	-0.0544
	sc	12	-0.0048
	sc	13	-0.1358
	sc	14	-0.0490
	sc	15	-0.1746

F-COPES:

ASS	sc	1	-0.0642

	sc	2	-0.1413
	sc	3	-0.0436
	sc	4	-0.0861
	sc	5	-0.2231
	sc	6	-0.0546
	sc	7	-0.2136
	sc	8	-0.3205**
	sc	9	-0.2166
	sc	10	-0.2477
	sc	11	-0.0721
	sc	12	-0.1140
	sc	13	-0.2391
	sc	14	-0.1480
	sc	15	-0.2614
R	sc	1	-0.0007
	sc	2	-0.1841
	sc	3	-0.1373
	sc	4	-0.1646
	sc	5	-0.0488
	sc	6	-0.1066
	sc	7	-0.1313
	sc	8	-0.2221
	sc	9	-0.2163
	sc	10	-0.2622
	sc	11	-0.1242
	sc	12	-0.0663
	sc	13	-0.1749
	sc	14	-0.0606
	sc	15	-0.1664
SSS	sc	1	-0.1531
	sc	2	-0.1176
	sc	3	-0.0468
	sc	4	-0.1881
	sc	5	-0.0133
	sc	6	-0.0040
	sc	7	-0.1982
	sc	8	-0.1099
	sc	9	-0.1192
	sc	10	-0.0918

	sc	11	-0.1677
	sc	12	-0.0280
	sc	13	-0.1276
	sc	14	-0.1732
	sc	15	-0.1305
MFAAH	sc	1	-0.0165
	sc	2	-0.1062
	sc	3	-0.0196
	sc	4	-0.1356
	sc	5	-0.0004
	sc	6	-0.0904
	sc	7	-0.0492
	sc	8	-0.1614
	sc	9	-0.0492
	sc	10	-0.0210
	sc	11	-0.0207
	sc	12	-0.1172
	sc	13	-0.0768
	sc	14	-0.0647
	sc	15	-0.1074
PA	sc	1	-0.2533
	sc	2	-0.0427
	sc	3	-0.1710
	sc	4	-0.0733
	sc	5	-0.1576
	sc	6	-0.0806
	sc	7	-0.0350
	sc	8	-0.1820
	sc	9	-0.0360
	sc	10	-0.2036
	sc	11	-0.1351
	sc	12	-0.1043
	sc	13	-0.1679
	sc	14	-0.0316
	sc	15	-0.0429

** p < 0.01

*** p < 0.001

The significant negative correlations reveal that the more a resource or coping pattern is used, the less the stress experienced.

The correlations displayed above were moderate, demonstrating significant relationships between certain stressors and a resource or coping pattern. Hypothesis 16, is therefore, supported.

5.9 Child Demographic Variables

Table 48 : Demographic information on four groups of children

Variable N	Asthma 30		Control 30		Leukaemia 23		Nephrotic 22	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
AGE BREAKDOWN :								
8 yrs	7	23.33	9	30.00	9	39.13	5	22.73
9yrs	11	36.67	7	23.33	9	39.13	5	22.73
10yrs	4	13.33	6	20.00	0	0.00	5	22.73
11yrs	5	16.67	5	16.67	2	8.70	5	22.73
12yrs	3	10.00	3	10.00	3	13.04	2	9.09
SEX :								
female	11	36.67	19	63.33	9	39.13	8	36.36
male	19	63.33	11	36.67	14	60.87	14	63.64*
STANDARD REACHED :								
class 1	0	0.00	1	3.33	2	8.70	0	0.00
class 2	2	6.67	4	13.33	3	13.04	4	18.18
std 1	7	23.33	7	23.33	7	30.43	6	27.27
std 2	9	30.00	6	20.00	6	26.09	2	9.09
std 3	5	16.67	4	13.33	2	8.70	5	22.73
std 4	6	20.00	5	16.67	0	0.00	2	9.09
std 5	1	3.33	2	6.67	1	4.35	3	13.64
std 6	0	0.00	1	3.33	1	4.35	0	0.00
special class	0	0.00	0	0.00	1	4.35	0	0.00
School absence	11	36.67	7	23.33	6	26.09	5	22.73
INTELL POTENTIAL :								
below average	5	16.67	4	13.33	8	43.78	5	22.73
average	18	60.00	18	60.00	10	43.48	10	45.45
above average	7	23.33	8	26.67	5	21.74	7	31.82
AGE OF DISEASE ONSET :								
<4	13	44.83	0	0.00	12	52.17	17	77.29
>4	16	55.17	29	100.00	11	47.83	5	22.73
NO. OF HOSPITAL ADMISSIONS IN LAST YEAR :								
0	24	80.00	28	93.33	19	82.61	17	77.27
1	6	20.00	2	6.67	2	8.70	4	18.18
2	0	0.00	0	0.00	1	4.35	1	4.55
3	0	0.00	0	0.00	0	0.00	0	0.00
4	0	0.00	0	0.00	1	4.35	0	0.00
PEER GROUP :	27	90.00	28	93.33	15	65.22	20	90.91*

* $p < 0.05$

Table 48 reflects the age distribution of children who fall into all age categories between 8 and 12 years.

Significantly more boys belonged to the asthmatic and nephrotic syndrome groups than girls.

In respect of maternal perception of intellectual potential, 60 per cent asthmatic and control, 45 per cent nephrotic syndrome, and 43 per cent leukaemic children were perceived as being of average intelligence. Surprisingly, there were no differences in the number of hospital admissions experienced by the different groups in the past twelve months. The leukaemic group experienced significantly fewer peer relationships.

5.10 A Comparison of the Coping Strategies of Four Groups of Children : Asthmatic, Leukaemic, Nephrotic Syndrome and Control

The present study was concerned with the coping strategies used by children with asthma, leukaemia, and nephrotic syndrome, and a control group. The frequency and percentages of the coping strategies are displayed below.

Table 49 : Frequencies and percentages of KIDCOPE responses of four groups of children

	Asthma		Control		Leukaemia		Nephrotic		
N	30		30		23		22		
Coping	Freq	Percent	Freq	Percent	Freq	Percent	Freq	Percent	P Value
Distraction	27	90.00	30	100.00	20	86.96	16	72.73	0.024*
Social withdrawal	16	53.33	11	36.67	16	69.57	13	59.09	0.108
Cognitive restructuring	28	93.33	27	90.00	19	82.61	18	81.82	0.517
Self criticism	15	50.00	12	40.00	11	47.83	11	50.00	0.854
Blaming others	4	13.33	5	16.67	3	13.04	3	13.64	0.978
Problem-solving	26	86.67	29	96.67	20	86.96	19	86.36	0.515
Emotional regulation	30	100.00	29	96.67	23	100.00	22	100.00	0.471
Wishful thinking	28	93.33	29	96.67	21	91.30	21	95.45	0.849
Social support	29	96.67	30	100.00	22	95.65	22	100.00	0.558
Resignation	12	40.00	13	43.33	11	47.83	12	54.55	0.754

* $p < 0.05$

A significant difference was noted among the four groups in respect of the frequency of use of distraction. The use of distraction was higher among the control group, followed by subjects with asthma and leukaemia. No other significant differences were noted.

5.11 Coping Strategies of Specific Illness and Control Children

Chi-square analyses were computed to examine the differences between children's coping in the specific illness groups and the control group. In instances when cells had expected counts less than 5, chi-square analysis was not considered a valid test. Fisher's exact test (2-tail) was, therefore, computed. The results are displayed in tables 50-52.

5.11.1 Asthmatic and Control Groups

Table 50 : Frequencies and percentages of KIDCOPE responses of asthmatic and control groups

	Asthma		Control		
N	30		30		
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	27	90.00	30	100.00	0.237
Social withdrawal	16	53.33	11	36.67	0.194
Cognitive restructuring	28	93.33	27	90.00	1.000
Self criticism	15	50.00	12	40.00	0.436
Blaming others	4	13.33	5	16.67	1.000
Problem-solving	26	86.67	29	96.67	0.353
Emotional regulation	30	100.00	29	96.67	1.000
Wishful thinking	28	93.33	29	96.67	1.000
Social support	29	96.67	30	100.00	1.000
Resignation	12	40.00	13	43.33	0.793

No significant differences were noted in the frequency of the coping strategies, thereby not supporting hypothesis 17.

5.11.2 Leukaemic and Control Groups

Table 51 : Frequencies and percentages of KIDCOPE responses of leukaemic and control groups

	Leukaemia		Control		
N		23		30	
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	20	86.96	30	100.00	0.076
Social withdrawal	16	69.57	11	36.67	0.018*
Cognitive restructuring	19	82.61	27	90.00	0.451
Self-criticism	11	47.83	12	40.00	0.569
Blaming others	3	13.04	5	16.67	0.305
Problem-solving	20	86.96	29	96.67	1.000
Emotional regulation	23	100.00	29	96.67	1.000
Wishful thinking	21	91.30	29	96.67	0.573
Social support	22	95.65	30	100.00	0.434
Resignation	11	47.83	13	43.33	0.745

* $p < 0.05$

The control group scored marginally higher than the leukaemic group on distraction. The leukaemic group scored significantly higher than the control group on social withdrawal. Hypothesis 17 is, therefore, supported.

5.11.3 Nephrotic Syndrome and Control Groups

Table 52 : Frequencies and percentages of KIDCOPE responses of nephrotic syndrome and control groups

		Nephrotic		Control	
N		23		30	
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	16	72.73	30	100.00	0.002**
Social withdrawal	13	59.09	11	36.67	0.109
Cognitive restructuring	18	81.82	27	90.00	0.438
Self-criticism	11	50.00	12	40.00	0.473
Blaming others	3	13.64	5	16.67	1.000
Problem-solving	19	86.36	29	96.67	0.299
Emotional regulation	22	100.00	29	96.67	1.000
Wishful thinking	21	95.45	29	96.67	1.000
Social support	22	100.00	30	100.00	.
Resignation	12	54.55	13	43.33	0.424

** $p < 0.01$

The control group scored significantly higher than the nephrotic syndrome group on distraction, thereby supporting hypothesis 17.

5.12 Chronically Ill and Control Children

The three chronic illness groups - asthma, leukaemia and nephrotic syndrome - were collapsed into one chronic illness group and compared with the control group. The results are displayed in Tables 53 and 54.

5.12.1 Child Demographic Variables

Table 53 : Demographic information on chronically ill and control children

Variable	Chronic illness		Control		
N	30		30		
	Freq	Percent	Freq	Percent	P Value
AGE BREAKDOWN :					
8 yrs	21	28.00	9	30.00	
9yrs	25	33.33	7	23.33	
10yrs	9	12.00	6	20.00	
11yrs	12	16.00	5	16.67	
12yrs	8	10.67	3	10.00	
SEX :					
female	28	37.33	19	63.33	
male	11	62.67	11	36.67	0.016*
School absence	22	29.33	7	23.33	
INTELL POTENTIAL :					
below average	18	24.00	4	13.33	
average	38	50.67	18	60.00	
above average	19	25.33	8	26.67	
NO. OF HOSPITAL ADMISSIONS IN LAST YEAR :					
0	60	80.00	28	93.33	
1	12	16.00	2	6.67	
2	2	2.67	0	0.00	
3	0	0.00	0	0.00	
4	1	1.33	0	0.00	
PEER GROUP :	62	82.67	28	93.33	

* $p < 0.05$

Significantly more males had chronic illness. No other significant differences were noted.

5.12.2 Coping Strategies of Chronically Ill and Control Children

To facilitate comparisons between the coping strategies of chronic illness and control group children, chi-square analyses were computed. Fisher's exact test (2-tail) was computed for cells with expected counts less than 5.

Table 54 : Frequencies and percentages of KIDCOPE responses of chronically ill and control groups

	Chronic illness		Control		
N	75		30		
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	63	84.00	30	100.00	0.018*
Social withdrawal	45	60.00	11	36.67	0.030*
Cognitive restructuring	65	86.67	27	90.00	0.753
Self-criticism	37	49.33	12	40.00	0.386
Blaming others	10	13.33	5	16.67	0.659
Problem-solving	65	87.67	29	96.67	0.172
Emotional regulation	75	100.00	29	96.67	1.286
Wishful thinking	70	93.33	29	96.67	0.671
Social support	73	97.33	30	100.00	1.000
Resignation	35	46.67	13	43.33	0.757

* $p < 0.05$

Significant differences were found between the chronically ill and control subjects on certain coping strategies, as can be observed from Table 54. In particular, the control subjects scored significantly higher than the chronic illness group on the strategy of "distraction". The chronically ill group scored significantly higher than the control group on the "social withdrawal" strategy. Hypothesis 18 is, therefore, supported.

The chronically ill group did not utilise coping strategies with significantly more than the control group, thereby not supporting hypothesis 18a.

5.13 Phase of Illness and Children's Coping Strategies

Chi-square analyses were computed to test for differences in the coping strategies used by children in the remission and induction sub-groups. Fisher's exact test (2- tail) was computed for cells with expected counts less than 5.

Table 55 : Frequencies and percentages of Kidcope responses and remission and induction scores

	Remission		Induction		
N		22		23	
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	19	86.36	17	73.91	0.459
Social withdrawal	16	72.73	13	65.52	0.256
Cognitive restructuring	16	72.73	21	91.30	0.103
Self criticism	14	63.64	8	34.78	0.053
Blaming others	4	18.18	2	8.70	0.414
Problem-solving	17	77.27	22	95.65	0.096
Emotional regulation	22	100.00	23	100.00	.
Wishful thinking	20	90.91	22	95.65	0.608
Social support	21	95.45	23	100.00	0.489
Resignation	12	54.55	11	47.83	0.652

There were no significant differences in the use of coping strategies by children in the remission and induction sub-groups. Hypothesis 19 is, therefore, not supported.

5.14 Gender and Children's Coping Strategies

To investigate the gender difference in the use of coping strategies, chi-square analyses were computed. Fisher's exact test was used for cells with expected counts less than 5.

Table 56 : Frequencies and percentages of Kidcope responses and scores of girls and boys

	Girls		Boys		
N	48		57		
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	43	89.58	50	87.72	0.765
Social withdrawal	23	47.92	33	57.89	0.307
Cognitive restructuring	43	89.58	49	85.96	0.575
Self criticism	19	39.58	30	52.63	0.182
Blaming others	5	10.42	10	17.54	0.298
Problem-solving	43	89.58	51	89.47	0.985
Emotional regulation	47	45.19	57	100.00	0.274
Wishful thinking	44	91.67	55	96.49	0.289
Social support	47	97.92	56	98.25	0.902
Resignation	20	41.67	28	49.12	0.445

As can be observed from Table 56, there were no significant differences between girls and boys in their choice of coping strategies. Hypotheses 20 and 20a are, therefore, not supported.

5.15 The Relationship between Children's Coping Strategies and Family Resources and Coping

The Student's t-test procedure was computed to determine the association between the frequency of children's coping strategies (as measured by Kidcope) and family resources and health-related and family coping patterns (measured by FIRM, CHIP and F-COPES, respectively). The results are displayed in Tables 57.1 to 57.10.

Table 57.1 : Means and standard deviations of KIDCOPE (distraction) and FIRM, CHIP and F-COPES scores

	KIDCOPE Distraction				
	Yes		No		
N	93		12		
	Mean	SD	Mean	SD	P Value
FIRM					
FS I	33.6021	6.613	35.8333	5.457	0.2131
FS II	37.2795	10.245	38.6666	10.316	0.6678
EFSS	8.6559	2.447	9.1666	2.249	0.4755
FWB	25.0537	10.821	26.3333	12.780	0.7453
SFS	4.3225	1.181	4.3333	1.497	0.9813
SD	13.4623	3.262	13.7500	2.301	0.7043
CHIP					
CP I	46.0967	7.518	48.0833	6.374	0.3357
CP II	17.9462	4.212	18.1666	3.663	0.8498
CP III	29.9462	9.075	29.0000	7.147	0.6821
F-COPES					
ASS	28.3655	8.504	29.5833	5.451	0.5079
R	32.1397	4.833	32.3333	7.278	0.9027
SSS	15.2043	4.132	17.1666	3.639	0.1043
MFAAH	12.2258	3.572	13.4166	3.287	0.2613
PA	7.0322	1.832	6.4166	2.065	0.3428

Table 57.2 : Means and standard deviations of KIDCOPE (social withdrawal) and FIRM, CHIP and F-COPES scores

KIDCOPE
Social Withdrawal

	Yes		No		
N	56		49		
	Mean	SD	Mean	SD	P Value
FIRM					
FS I	33.4642	6.690	34.3061	6.331	0.5095
FS II	36.1428	11.018	38.9183	9.094	0.1605
EFSS	8.6964	2.723	8.7346	2.049	0.9361
FWB	25.2500	10.411	25.1428	11.747	0.9609
SFS	4.3035	1.320	4.3469	1.090	0.8542
SD	13.0357	3.400	14.0204	2.802	0.1070
CHIP					
CP I	46.0357	7.288	46.6530	7.578	0.6725
CP II	17.9107	4.218	18.0408	4.087	0.8730
CP III	28.7321	8.904	31.1020	8.708	0.1717
F-COPES					
ASS	27.6607	8.488	29.4693	7.837	0.2591
R	31.8214	5.260	32.5510	4.991	0.4679
SSS	15.2142	4.097	15.6734	4.155	0.5709
MFAAH	11.8928	3.366	12.8979	3.703	0.1510
PA	6.9464	1.976	6.9795	1.737	0.9273

Table 57.3 : Means and standard deviations of KIDCOPE (cognitive restructuring) and FIRM, CHIP and F-COPES scores

KIDCOPE
Cognitive Restructuring

	Yes		No		
N	92		13		
	Mean	SD	Mean	SD	P Value
FIRM					
FS I	3.9239	6.558	33.3846	6.371	0.7796
FS II	37.0000	10.455	40.5388	7.943	0.1668
EFSS	8.7173	2.512	8.6923	1.702	0.9634
FWB	24.8478	10.969	27.6923	11.345	0.4086
SFS	4.2934	1.227	4.5384	1.126	0.4784
SD	13.4673	3.146	13.6923	3.376	0.8237
CHIP					
CP I	46.1630	7.565	47.4615	6.199	0.5015
CP II	17.8152	4.291	19.0769	2.691	0.1614
CP III	29.9891	8.997	28.7692	7.980	0.6185
F-COPES					
ASS	28.5000	8.348	28.5384	7.378	0.9864
R	32.1630	5.043	32.1538	5.899	0.9958
SSS	15.2826	4.095	16.4615	4.235	0.3602
MFAAH	12.2826	3.611	12.9230	3.121	0.5067
PA	6.9565	1.892	7.0000	1.683	0.9327

Table 57.4 : Means and standard deviations of KIDCOPE (self-criticism) and FIRM, CHIP and F-COPES scores

KIDCOPE
Self-criticism

	Yes		No		
N	49		56		
	Mean	SD	Mean	SD	P Value
FIRM					
FS I	33.9591	6.441	33.7678	6.622	0.8812
FS II	37.2040	10.503	37.6428	10.042	0.8279
EFSS	8.6938	2.123	8.7321	2.673	0.9351
FWB	23.1632	11.301	26.9821	10.509	0.0774
SFS	4.1224	1.053	4.5000	1.321	0.1067
SD	13.6938	3.513	13.3214	2.835	0.5551
CHIP					
CP I	44.6122	7.410	47.8214	7.114	0.0263*
CP II	17.7755	4.292	18.1428	4.029	0.6536
CP III	28.9183	8.693	30.6428	8.987	0.3206
F-COPES					
ASS	29.0612	8.547	28.0178	7.932	0.5203
R	31.8163	4.697	32.4642	5.496	0.5164
SSS	15.3673	4.414	15.4821	3.865	0.8883
MFAAH	12.4693	3.530	12.2678	3.590	0.7728
PA	6.7551	1.639	7.1428	2.030	0.2820

* $p < 0,05$

Table 57.5 : Means and standard deviations of KIDCOPE (blaming others) and FIRM, CHIP and F-COPES scores

KIDCOPE
Blaming Others

	Yes		No		
N	15		90		
	Mean	SD	Mean	SD	P Value
FIRM					
FS I	32.8000	8.001	34.0333	6.261	0.5770
FS II	38.6000	7.641	37.2444	10.603	0.5556
EFSS	7.4666	2.587	8.9222	2.342	0.0559*
FWB	25.2666	9.624	25.1888	11.262	0.9777
SFS	4.6666	1.046	14.2666	1.234	0.1965
SD	12.8666	3.795	13.6000	3.053	0.4867
CHIP					
CP I	46.6666	8.723	46.2666	7.206	0.8683
CP II	16.0000	5.104	18.3000	3.910	0.1088
CP III	28.1333	11.500	30.1222	8.377	0.5297
F-COPES					
ASS	29.0666	10.123	28.9111	7.830	0.3141
R	34.0666	3.514	31.8444	5.295	0.0469*
SSS	14.2000	4.229	15.6333	4.079	0.2372
MFAAH	10.3333	2.845	12.7000	2.552	0.0089**
PA	6.9333	1.279	6.9666	1.945	0.9324

* $p < 0.05$
** $p < 0.01$

Table 57.6 : Means and standard deviations of KIDCOPE (problem-solving) and FIRM, CHIP and F-COPES scores

KIDCOPE
Problem-solving

	Yes		No		
N	94		11		
	Mean	SD	Mean	SD	P Value
FIRM					
FS I	33.5957	6.392	36.0909	7.368	0.3031
FS II	37.5212	9.795	36.7272	13.849	0.8567
EFSS	8.5957	2.490	9.7272	1.420	0.0359*
FWB	24.7127	10.662	29.3636	13.418	0.2900
SFS	4.3297	1.176	4.2727	1.555	0.9083
SD	13.5638	2.982	12.9090	4.548	0.5181
CHIP					
CP I	46.3510	7.231	46.0909	9.312	0.9295
CP II	17.7872	4.175	19.5454	3.587	0.1543
CP III	29.5957	8.596	31.9090	11.058	0.5158
F-COPES					
ASS	27.5000	7.730	37.0909	7.300	0.0013**
R	32.2446	4.785	31.4545	7.724	0.6309
SSS	15.2872	4.136	16.6363	3.854	0.2958
MFAAH	12.1063	3.361	14.5454	4.457	0.1058
PA	7.0319	1.880	6.3636	1.629	0.2275

* $p < 0.05$
** $p < 0.01$

Table 57.7 : Means and standard deviations of KIDCOPE (emotional regulation) and FIRM, CHIP and F-COPES scores

KIDCOPE
Emotional Regulation

	Yes		No		
N	104		1		
	Mean	SD	Mean	SD	P Value
FIRM					
FS I	33.8750	6.536	32.0000	-	0.7759
FS II	37.3942	1.025	42.0000	-	0.6558
EFSS	8.7019	2.429	10.0000	-	0.5960
FWB	25.2788	1.102	17.0000	-	0.4566
SFS	4.3269	1.218	4.0000	-	0.7900
SD	13.5096	3.171	12.0000	-	0.6367
CHIP					
CP I	46.3173	7.431	47.0000	-	0.9273
CP II	18.0096	4.139	14.0000	-	0.3373
CP III	29.8076	8.888	33.0000	-	0.7215
F-COPES					
ASS	28.3942	8.162	40.0000	-	0.1601
R	32.1634	5.150	32.0000	-	0.9749
SSS	15.3942	4.115	19.0000	-	0.3853
MFAAH	12.3557	3.563	13.0000	-	0.8576
PA	6.9807	1.859	5.0000	-	0.2914

Table 57.8 : Means and standard deviations of KIDCOPE (wishful thinking) and FIRM, CHIP and F-COPES scores

KIDCOPE
Wishful Thinking

	Yes		No		
N	99		6		
	Mean	SD	Mean	SD	P Value
FIRM					
FS I	33.8282	6.521	34.3333	6.860	0.8669
FS II	36.9696	10.157	45.1666	8.447	0.0637
EFSS	8.7373	2.401	8.3333	2.943	0.7542
FWB	24.6969	10.908	33.5000	9.874	0.0818
SFS	4.2626	1.217	5.3333	0.516	0.0351*
SD	13.3535	3.140	15.8333	2.714	0.0763
CHIP					
CP I	46.1212	7.497	49.6666	4.676	0.1301
CP II	17.9595	4.162	18.1666	4.070	0.9080
CP III	30.0909	8.936	25.6666	6.501	0.1640
F-COPES					
ASS	28.7272	8.248	24.8333	6.986	0.2379
R	32.0202	5.132	34.5000	4.806	0.2699
SSS	15.4444	4.083	15.1666	4.956	0.8979
MFAAH	12.5252	3.532	9.6666	2.804	0.0544*
PA	6.9393	1.888	7.3333	1.366	0.5279

* $p < 0.05$

Table 57.9 : Means and standard deviations of KIDCOPE (social support) and FIRM, CHIP and F-COPES scores

KIDCOPE
Social Support

	Yes		No		
N	103		2		
	Mean	SD	Mean	SD	P Value
FIRM					
FS I	33.8058	6.542	36.5000	4.949	0.5834
FS II	37.5242	10.014	33.0000	24.041	0.5375
EFSS	8.7281	2.438	8.0000	1.414	0.6012
FWB	25.2427	11.032	23.0000	12.727	0.8451
SFS	4.3300	1.215	4.0000	1.414	0.7977
SD	13.5339	3.114	11.5000	6.363	0.7300
CHIP					
CP I	46.4563	7.365	39.5000	7.778	0.4254
CP II	17.9805	4.177	17.5000	0.707	0.5165
CP III	29.8155	8.896	31.0000	8.485	0.8766
F-COPES					
ASS	28.4174	8.252	33.0000	2.828	0.2401
R	32.1359	5.167	33.5000	2.121	0.5310
SSS	15.4368	4.141	15.0000	2.828	0.8645
MFAAH	12.2912	3.544	16.0000	-	0.1438
PA	6.9514	1.875	7.5000	0.707	0.4678

Table 57.10 : Means and standard deviations of KIDCOPE (resignation) and FIRM, CHIP and F-COPES scores

KIDCOPE
Resignation

	Yes		No		
N	48		57		
	Mean	SD	Mean	SD	P Value
FIRM					
FS I	34.5000	5.619	33.3157	7.176	0.3455
FS II	36.7708	11.430	38.0000	9.130	0.5494
EFSS	9.2291	2.065	8.2807	2.623	0.0408*
FWB	24.8750	10.789	25.4736	11.264	0.7819
SFS	4.2291	1.076	4.4035	1.320	0.4580
SD	13.7708	3.353	13.2631	2.997	0.4194
CHIP					
CP I	45.7916	7.505	46.7719	7.338	0.5022
CP II	17.3333	3.766	18.5087	4.387	0.1427
CP III	29.4583	8.389	30.1578	9.284	0.6861
F-COPES					
ASS	28.8750	8.052	28.1929	8.384	0.6723
R	32.5208	5.343	31.8596	4.962	0.5156
SSS	15.3125	4.238	15.5263	4.036	0.7930
MFAAH	11.7708	3.656	12.8596	3.403	0.1200
PA	6.6250	2.140	7.2456	1.550	0.0886

* $p < 0.05$

Significant associations were found between the frequency of children's coping and certain family resources and health-related and family coping patterns.

Hypothesis 21 is, therefore, supported.

5.16 A Comparison of the Self-Esteem of Children with Asthma, Leukaemia, Nephrotic Syndrome and Control Children

Analyses of variance were computed to test for significance among the four groups on the measure of self-esteem. Significant differences were noted on the dimensions of "social acceptance" and "behavioural conduct" with marginal significance noted on "scholastic competence" and "self-worth."

Table 58 : Means and standard deviations of "What I am like" scores of four groups of children

	Asthma		Leukaemic		Nephrotic		Control			
N	30		23		22		30			
Self-Esteem	Mean	SD	Mean	SD	Mean	SD	Mean	SD	F	P
Scholastic	2.853	0.801	2.521	0.657	2.881	0.584	3.040	0.663	2.50	0.0635
Social	2.774	0.645	2.765	0.747	2.754	0.591	3.293	0.483	5.50	0.0015**
Athletic	2.438	0.708	2.630	0.592	2.462	0.584	2.488	0.719	0.41	0.7455
Physical	2.983	0.686	2.818	0.651	2.909	0.597	3.094	0.576	0.90	0.4443
Behaviour	2.853	0.610	2.634	0.574	2.981	0.681	3.386	0.535	7.63	0.0001***
Self worth	3.038	0.688	2.862	0.634	3.015	0.590	3.350	0.679	2.65	0.0526

** $p < 0.01$

*** $p < 0.001$

Duncan's multiple range test for pairwise comparisons was used to isolate significant difference among the four groups on "social acceptance" and "behavioural conduct," and on the dimensions of "scholastic competence" and "self-worth."

Table 58.1 : Results of the Duncan's multiple range test : Social acceptance

Group	N	Mean	Duncan Grouping
Control	30	3.2933	A
Leukaemic	23	2.7652	B
Nephrotic	22	2.7545	B
Asthmatic	30	2.7400	B

The control subjects scored significantly higher than the leukaemic, nephrotic syndrome and asthmatic subjects on "social acceptance."

Table 58.2 : Results of the Duncan's multiple range test : Behavioural conduct

Group	N	Mean	Duncan Grouping
Control	30	3.3867	A
Nephrotic	22	2.9818	B
Asthmatic	30	2.8533	B
Leukaemic	23	2.6348	B

The control subjects scored significantly higher than the nephrotic syndrome, asthmatic and leukaemic subjects on this dimension.

Table 58.3 : Results of the Duncan's multiple range test : Scholastic competence

Group	N	Mean	Duncan Grouping
Control	30	3.0400	A
Nephrotic	22	2.8818	A
Asthmatic	30	2.8533	B
Leukaemic	23	2.5217	B

The results reveal that the control subjects scored significantly higher than the leukaemic and asthmatic subjects on "scholastic competence."

Table 58.4 : Results of the Duncan's multiple range test : Self-worth

Group	N	Mean	Duncan Grouping
Control	30	3.3500	A
Asthmatic	30	3.0389	B A
Nephrotic	22	3.0152	B A
Leukaemic	23	2.8623	B

The control subjects scored significantly higher than the leukaemic subjects on "self-worth."

Hypothesis 22 is, therefore, supported.

5.17 Self-Esteem of Chronically Ill and Control Children

The three chronic illness groups were collapsed into one illness group and compared, using the t-test procedure, with the control group of non chronically ill subjects. The results are displayed in Table 59.

Table 59 : Means and standard deviations of "What am I like" scores of chronically ill and control children

	Chronic Illness		Control		
N	75		30		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.7600	0.709	3.0400	0.663	0.0604
Social acceptance	2.7520	0.654	3.2933	0.483	0.0001***
Athletic competence	2.5044	0.633	2.4888	0.719	0.9180
Physical appearance	2.9111	0.645	3.0944	0.576	0.1606
Behavioural conduct	2.8240	0.628	3.3866	0.535	0.0001***
Self-worth	2.9777	0.641	3.3500	0.679	0.0130*

* $p < 0.05$

*** $p < 0.001$

The control subjects scored significantly higher on "social acceptance," "behavioural conduct" and "self-worth" than the chronic illness subjects. Hypothesis 23 is, therefore, supported.

5.18 Phase of Illness and Children's Self-Esteem

The results of the t-test procedure used to determine differences in self-esteem between children in the phases of remission and induction are presented in Table 60. Subjects in the induction group scored significantly higher than those in remission on "behavioural conduct. "Hypothesis 24 is, therefore, supported.

Table 60 : Means and standard deviations of "What am I like" and remission and induction scores

	Phase of Illness				
	Remission		Induction		
N	22		23		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.6090	0.683	2.7826	0.602	0.3722
Social acceptance	2.8818	0.721	2.6434	0.605	0.2381
Athletic competence	2.6287	0.706	2.4710	0.448	0.3741
Physical appearance	2.7121	0.725	3.0072	0.470	0.1112
Behavioural conduct	2.6090	0.596	2.9913	0.648	0.0455*
Self-worth	2.8939	0.567	2.9782	0.661	0.6481

* $p < 0.05$

5.19 Gender and Children's Self-Esteem

Girls scored significantly higher than boys on the "scholastic competence" and "behavioural conduct" dimensions, thereby supporting hypothesis 25.

Table 61 : Means and standard deviations of "What am I like" scores of girls and boys

	Girls		Boys		
N	48		57		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.9875	0.658	2.7157	0.724	0.0467*
Social acceptance	2.8958	0.722	2.9157	0.601	0.8795
Athletic competence	2.4409	0.633	2.5497	0.674	0.3971
Physical appearance	3.0416	0.603	2.8976	0.648	0.2420
Behavioural conduct	3.1250	0.631	2.8666	0.651	0.0423*
Self-worth	3.1493	0.715	3.0292	0.631	0.3687

* $p < 0.05$

5.20 The Relationship between Children's Self-Esteem and Children's Coping Strategies

The t-test procedure was used to determine whether any associations exist between the self-esteem dimensions and coping strategies.

As the Kidcope measure taps categorical data, statistical procedures such as the Pearson correlation technique could not be performed. The results are displayed in Tables 62.1 to 62.10.

Table 62.1 : Means and standard deviations of KIDCOPE (distraction) and "What am I like" scores

	Kidcope Distraction				
	Yes		No		
N	93		12		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8172	0.703	3.0166	0.720	0.3812
Social acceptance	2.8924	0.655	3.0166	0.684	0.5620
Athletic competence	2.5161	0.664	2.3750	0.590	0.4550
Physical appearance	2.9265	0.615	3.2500	0.694	0.0941
Behavioural conduct	2.9548	0.656	3.2166	0.593	0.1765
Self-worth	3.0591	0.669	3.2777	0.675	0.3088

There were no significant differences in the self-esteem of children who used the "distraction" coping strategy and those who did not.

Table 62.2 : Means and standard deviations of KIDCOPE (social withdrawal) and "What am I like" scores

	Kidcope Social Withdrawal				
	Yes		No		
N	56		49		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.7642	0.685	2.9265	0.723	0.2427
Social acceptance	2.8250	0.592	3.0000	0.717	0.1799
Athletic competence	2.5119	0.686	2.4863	0.624	0.8424
Physical appearance	2.8333	0.672	3.1122	0.545	0.0210*
Behavioural conduct	2.8892	0.663	3.0938	0.628	0.1081
Self-worth	2.9642	0.625	3.2210	0.700	0.0517

* $p < 0.05$

There was a significant association between the "social withdrawal" coping strategy and the "physical appearance" dimension. Subjects who did not use the "social withdrawal" coping strategy indicated better physical appearance than those who used the strategy.

There was a marginally significant association between the "social withdrawal" coping strategy and the "self-worth" dimension. Subjects who did not use the "social withdrawal" coping strategy indicated higher self-worth than those who used the strategy.

Table 62.3 : Means and standard deviations of KIDCOPE (cognitive restructuring) and "What am I like" scores

	Kidcope Cognitive Restructuring				
	Yes		No		
N	92		13		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8413	0.689	2.8307	0.836	0.9660
Social acceptance	2.9173	0.647	2.8307	0.738	0.6938
Athletic competence	2.4510	0.643	2.8461	0.657	0.0597
Physical appearance	2.9746	0.638	2.8846	0.582	0.6135
Behavioural conduct	2.9891	0.665	2.9538	0.578	0.8424
Self-worth	3.0815	0.668	3.1025	0.725	0.9225

A marginally significant association was observed between the "cognitive restructuring" coping strategy and the "athletic competence" dimension. Subjects who did not use the "cognitive restructuring" coping strategy indicated better athletic competence than those who used the strategy.

Table 62.4 : Means and standard deviations of KIDCOPE (self-criticism) and "What am I like" scores

	Kidcope Self criticism				
	Yes		No		
N	49		56		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8285	0.694	2.8500	0.719	0.8770
Social acceptance	2.8489	0.644	2.9571	0.667	0.4011
Athletic competence	2.4795	0.690	2.5178	0.628	0.7684
Physical appearance	2.8503	0.660	3.0625	0.589	0.0875
Behavioural conduct	2.8530	0.675	3.1000	0.614	0.0542
Self-worth	2.9625	0.689	3.1904	0.641	0.0840

Marginally significant associations were observed between the "self-criticism" coping strategy and "physical appearance," and between "self-criticism" and "behavioural conduct," and "self-criticism" and the "self-worth" dimensions. Subjects who did not use the "self-criticism" strategy indicated good physical appearance, good behaviour and higher self-worth than those who used the strategy.

Table 62.5 : Means and standard deviations of KIDCOPE (blaming others) and "What am I like" scores

	Kidcope Blaming Others				
	Yes		No		
N	15		90		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8400	0.615	2.8400	0.721	1.0000
Social acceptance	2.6933	0.554	2.9422	0.667	0.1336
Athletic competence	2.4111	0.742	2.5148	0.643	0.6163
Physical appearance	2.9555	0.589	2.9648	0.639	0.9562
Behavioural conduct	3.1466	0.639	2.9577	0.654	0.3040
Self-worth	3.1555	0.554	3.0722	0.690	0.6090

There were no significant differences in the self-esteem of children who used the "blaming others" coping strategy and those who did not.

Table 62.6 : Means and standard deviations of KIDCOPE (problem-solving) and "What am I like" scores

	Kidcope Problem Solving				
	Yes		No		
N	94		11		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8574	0.706	2.6909	0.700	0.4699
Social acceptance	2.9191	0.657	2.8000	0.663	0.5827
Athletic competence	2.4875	0.673	2.6060	0.478	0.4710
Physical appearance	2.9414	0.637	3.1515	0.550	0.2596
Behavioural conduct	3.0148	0.640	2.7272	0.728	0.2338
Self-worth	3.0549	0.677	3.3333	0.577	0.1609

There were no significant differences in the self-esteem of children who used the "problem-solving" coping strategy and those who did not.

Table 62.7 : Means and standard deviations of KIDCOPE (emotional regulation) and "What am I like" scores

	Kidcope Emotional Regulation				
	Yes		No		
N	104		1		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8461	7.0517	2.2000	-	0.3639
Social acceptance	2.9096	6.5884	2.6000	-	0.6410
Athletic competence	2.5000	6.5852	2.5000	-	1.0000
Physical appearance	2.9727	6.2538	2.0000	-	0.1247
Behavioural conduct	2.9923	6.5116	2.2000	-	0.2287
Self-worth	3.0897	6.7147	2.5000	-	0.4841

There were no significant differences in the self-esteem of children who used the "emotional regulation" coping strategy and those who did not.

Table 62.8 : Means and standard deviations of KIDCOPE (wishful thinking) and "What I am like" scores

	Kidcope Wishful Thinking				
	Yes		No		
N	99		6		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8464	0.719	2.7333	0.413	0.5571
Social acceptance	2.9070	0.663	2.9000	0.576	0.9779
Athletic competence	2.4831	0.663	2.7777	0.443	0.1742
Physical appearance	2.9646	0.642	2.9444	0.389	0.9098
Behavioural conduct	2.9696	0.660	3.2333	0.480	0.2486
Self-worth	3.0757	0.659	3.2222	0.904	0.7115

There were no significant differences in the self-esteem of children who used the "wishful thinking" coping strategy and those who did not.

Table 62.9 : Means and standard deviations of KIDCOPE (social support) and "What am I like" scores

	Kidcope Social Support				
	Yes		No		
N	103		2		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8485	0.699	2.4000	1.131	0.6750
Social acceptance	2.9281	0.643	1.8000	0.282	0.0993
Athletic competence	2.4951	0.648	2.7500	1.296	0.8276
Physical appearance	2.9660	6.354	2.8333	0.000	0.7694
Behavioural conduct	2.9961	6.537	2.4000	0.000	0.2022
Self-worth	3.0906	0.675	2.7500	0.117	0.0614

A marginal significance was noted between the "social support" coping strategy and "self-worth" dimension. Subjects who used the "social support" coping strategy indicated higher self-worth than those who did not use the strategy.

Table 62.10 : Means and standard deviations of KIDCOPE (resignation) and "What am I like" scores

	Kidcope Resignation				
	Yes		No		
N	48		57		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8458	0.634	2.8350	0.764	0.9374
Social acceptance	2.9791	0.570	2.8456	0.720	0.2917
Athletic competence	2.4236	0.700	2.5643	0.613	0.2808
Physical appearance	2.9409	0.670	2.9824	0.598	0.7409
Behavioural conduct	2.9625	0.704	3.0035	0.611	0.7531
Self-worth	3.0694	0.677	3.0964	0.671	0.8382

There were no significant differences in the self-esteem of children who used the "resignation" coping strategy and those who did not.

The significant results are supportive of hypothesis 26.

5.21 The Relationship between Children's Self-Esteem and Self-Worth

Pearson correlation coefficients (r) were computed, across all subjects, for each self-esteem dimension and self-worth count to determine the strength of the associations.

Table 63 : Correlations between "What am I like" and self-worth scores

	Self Worth
Total sample	105
Self-Esteem	
Scholastic competence	0.4162***
Social acceptance	0.1703
Athletic competence	0.0716
Physical appearance	0.5286***
Behavioural conduct	0.3522***

*** $p < 0.001$

Moderate positive correlations were observed, demonstrating a relationship between the self-esteem dimensions of "scholastic competence" and "self-worth,""physical appearance" and "self-worth" and "behavioural conduct" and "self-worth". These results support hypothesis 27.

5.22 The Relationship between Children's Self-Esteem and Family Resources and Coping

Pearson correlation coefficients (r) were computed, across all subjects for each self-esteem count with each resource and coping dimension (as measured by FIRM, CHIP and F-COPES) to determine the strength of associations.

All the correlations were weak, demonstrating a poor relationship between children's self-esteem and resources and family coping. Hypothesis 28 is, therefore, not supported.

5.23 Additional Data Related to Family Stress, Resources, Coping, and Adaptation

Student's t-tests were also used to examine the relationship of the following additional variables to stress, resources, and coping. The variables examined were:

- age of disease onset,
- maternal perception of severity of the child's condition,
- maternal perception of the life expectancy of the child,
- maternal education, and,
- medical knowledge.

The results are depicted in Tables 64 to 68.

5.23.1 Age of Disease Onset and Family Life Events and Changes

The differences in life events in families whose children developed chronic illness in early and middle childhood was examined.

Table 64 : Means and standard deviations of early and middle childhood and FILE scores

	Age of Onset				
	Early Childhood (0-4yrs)		Middle Childhood (5-12yrs)		
N	39		56		
FILE	Mean	SD	Mean	SD	P Value
Total Scale	8.5128	4.784	9.5535	5.591	0.3468

No significant differences were found.

5.23.1.1 Age of Disease Onset and Stress and Resources

To investigate the difference in stress and resources between families with children who developed chronic disease in early and middle childhood, t-tests were computed.

Table 65 : Means and standard deviations of early and middle childhood and QRS scores

		Age of Onset				
N		Early Childhood (0-4yrs) 39		Middle Childhood (5-12yrs) 56		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	4.2051	3.130	4.2857	2.896	0.8976
2	Excess time demands	6.6153	2.529	5.6250	2.611	0.0687
3	Negative attitude toward index case	8.2051	3.671	8.1070	3.462	0.8950
4	Overprotection/dependency	4.9487	2.293	5.0178	2.518	0.8918
5	Lack of social support	2.1538	1.646	2.3214	1.415	0.5970
6	Overcommitment/martyrdom	4.7692	1.422	4.5535	1.559	0.4939
7	Pessimism	2.4871	1.876	2.9285	2.173	0.3062
8	Lack of family integration	3.5384	1.997	3.4285	2.592	0.8244
9	Limits of family opportunity	1.7692	1.966	1.8571	1.699	0.8167
10	Financial problems	5.3589	3.889	5.7321	3.498	0.6264
11	Physical incapacitation	3.1025	1.682	2.7321	1.601	0.2801
12	Lack of activities for index case	1.6153	1.269	1.7678	1.293	0.5703
13	Occupational limitation	2.0000	1.432	1.8392	1.290	0.5696
14	Social obtrusiveness	1.1538	0.960	1.2321	0.972	0.6989
15	Difficult personality characteristics	6.4615	3.485	6.2321	3.618	0.7583

Table 65 indicates that in respect of age of onset, there was no significant differences in the stress and resources in families experiencing chronic childhood disease.

5.23.1.2 Age of Disease Onset and Resources for Management

Student's t-tests were used to examine the management of resources between families with children who developed chronic disease in early and middle childhood.

Table 66 : Means and standard deviations of early and middle childhood and FIRM scores

	Early Childhood (0-4yrs)		Middle Childhood (5-12yrs)		
N	39		56		
Resource	Mean	SD	Mean	SD	P Value
FS I	35.2307	6.994	32.9464	5.801	0.0862
FS II	40.0512	10.412	34.9821	9.426	0.0153*
EFSS	9.3076	2.066	8.1964	2.638	0.0302*
FWB	27.4615	11.243	24.5357	10.231	0.1913
SFS	4.4358	1.187	4.3214	1.192	0.6459
SD	13.9230	2.756	13.035	3.258	0.1682

* $p < 0.05$

Subjects in the early childhood onset group scored significantly higher than those in the middle childhood onset group on the resources of family strength II: mastery and health (FS II) and the extended family social support resource (EFSS).

5.23.1.3 Age of Disease Onset and Health-Related Coping Patterns

Table 67 displays the results of the t-tests used to determine the differences in illness-related coping patterns between families of children who developed chronic illness in early and middle childhood. A missing observation was noted in the middle childhood group.

Table 67 : Means and standard deviations of early and middle childhood and CHIP scores

	Age of Onset				
	Early Childhood (0-4yrs)		Middle Childhood (5-12yrs)		
N	3948		56		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	48.5128	6.544	45.418	7.687	0.0440*
CP II	30.9487	8.893	29.5636	9.120	0.4655
CP III	19.5128	3.493	17.0545	4.240	.0038**

* $p < 0.05$

** $p < 0.01$

As depicted, subjects in the early childhood onset group scored significantly higher than those in the middle childhood onset group on coping patterns I and II.

5.23.1.4 Age of Disease Onset and Family Crisis Oriented Coping Strategies

Table 68 displays the results of the t-tests which were computed to determine differences in the family crisis-oriented coping strategies of families with children who developed chronic disease in early and middle childhood.

Table 68 : Means and standard deviations of early and middle childhood and F-COPES scores

	Early Childhood (0-4yrs)		Middle Childhood (5-12yrs)		
N	39		56		
Coping Strategy	Mean	SD	Mean	SD	P Value
ASS	29.1538	8.493	27.9821	7.870	0.4913
R	32.0000	5.462	32.3214	4.767	0.7615
SSS	15.9230	3.716	14.8392	4.547	0.2221
MFAAH	12.6153	3.543	12.1250	3.618	0.5139
PA	7.0769	2.181	6.8035	1.656	0.4894

There were no significant differences in the family crisis-oriented coping strategies between subjects in the early and middle childhood onset groups.

5.23.2 Perception of Severity of Symptoms and Stress and Resources

The Student's t-tests were conducted to investigate the differences, if any, in stress and resources between families who perceived their children to have symptoms and those who did not were examined. Significant differences were noted as depicted in Table 69.

Table 69 : Means and standard deviations of "no symptoms" and "symptoms" and QRS scores

		Severity of Symptoms				
N		No Symptoms		Symptoms		
		54		50		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	3.4444	2.872	5.2200	2.823	0.0020**
2	Excess time demands	5.6111	2.490	6.6400	2.488	0.0377**
3	Negative attitude toward index case	7.6481	3.286	9.0600	3.542	0.0380*
4	Overprotection/dependency	4.2962	2.407	6.0200	2.171	0.0002**
5	Lack of social support	2.0925	1.335	2.5200	1.681	0.1566
6	Overcommitment/martyrdom	4.3333	1.590	5.0200	1.253	0.0158*
7	Pessimism	2.4814	1.645	3.0400	2.355	0.1676
8	Lack of family integration	3.2777	2.277	3.5800	2.458	0.5179
9	Limits of family opportunity	1.5740	1.711	2.2000	1.905	0.0820
10	Financial problems	5.0740	3.544	6.3800	3.602	0.0656
11	Physical incapacitation	2.1481	1.309	3.5200	1.501	0.0001***
12	Lack of activities for index case	1.3518	0.993	2.2400	1.363	0.0002***
13	Occupational limitation	1.8148	1.388	2.0000	1.309	0.4855
14	Social obtrusiveness	1.1296	1.046	1.2800	0.969	0.4488
15	Difficult personality characteristics	5.5740	3.117	7.3600	3.863	0.0114*

* $p < 0.05$
** $p < 0.01$
*** $p < 0.001$

Subjects in the "symptoms" group scored significantly higher than subjects in the "no symptoms" group on the poor health/mood,

excess time demands, negative attitude toward index case, overprotection/dependency, overcommitment/martyrdom, physical incapacitation, lack of activities for index case, and difficult personality characteristics scales, and marginally higher on the financial problems scale.

5.23.2.1 Perception of Severity of Symptoms and Resources for Management

Student's t-tests were conducted to determine differences in the management of resources between families who perceived their children to have symptoms and those who did not.

Table 70 : Means and standard deviations of "no symptoms" and "symptoms" and FIRM scores

	Severity of Symptoms				
	No Symptoms		Symptoms		
N	54		50		
Resource	Mean	SD	Mean	SD	P Value
FS I	35.2407	6.474	32.720	6.259	0.0465*
FS II	38.8518	9.989	35.620	10.10	0.1042
EFSS	8.7037	2.27	8.780	2.620	0.8742
FWB	27.0185	11.63	22.880	9.900	0.0544
SFS	4.4629	1.076	4.140	1.340	0.1770
SD	13.5555	3.190	13.400	3.168	0.8037

* $p < 0.05$

As indicated in Table 70, subjects in the "no symptoms" group scored significantly higher than subjects in the "symptoms" group on the resource of family strength I: esteem and communication (FS I).

5.23.2.2 Perception of Severity of Symptoms and Health-Related Coping Patterns

Student's t-tests were computed to investigate differences in the use of coping patterns between families who perceived their children to have symptoms and those who did not.

Table 71 : Means and standard deviations of "no symptoms" and "symptoms" and CHIP scores

	Severity of Symptoms				
	No Symptoms		Symptoms		
N	54		50		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	47.7962	7.431	44.8979	7.257	0.0483*
CP II	31.5555	9.370	28.3877	7.854	0.0674
CP III	18.1481	4.306	17.6938	3.895	0.5771

* $p < 0.05$

Subjects in the "no symptoms" group scored significantly higher than those in the "symptoms" group on coping pattern I.

5.23.2.3 Perception of Severity of Symptoms and Family Crisis-Oriented Coping Strategies

Table 72 reveals the results of the t-tests used to investigate differences in coping strategies between families who perceived their children to have symptoms and those who did not.

Table 72 : Means and standard deviations of "no symptoms" and "symptoms" and F-COPES scores

	Severity of Symptoms				
	No Symptoms		Symptoms		
N	54		50		
Coping Strategy	Mean	SD	Mean	SD	P Value
ASS	28.7777	7.715	28.1200	8.763	0.6849
R	32.6481	5.220	31.6600	5.024	0.3284
SSS	15.7407	3.895	14.8200	4.387	0.2597
MFAAH	12.3888	3.520	12.4800	3.258	0.8915
PA	7.0555	2.095	6.8600	1.590	0.5954

No significant differences in the use of family coping strategies were found between subjects in the "no symptoms" and "symptoms groups."

5.23.3 Perceived Life Expectancy and Stress and Resources

Student's t-tests were computed to investigate the differences in stress between families who perceived their children to have normal life expectancy and those who were uncertain.

Table 73 : Means and standard deviations of "normal" and "uncertain" life expectancy and QRS scores

		Life Expectancy				
		Normal		Uncertain		
N		55		49		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	3.7636	3.048	4.8979	2.793	0.0516*
2	Excess time demands	5.2727	2.445	7.0408	2.309	0.0003***
3	Negative attitude toward index case	7.5272	3.219	9.2244	3.548	0.0120*
4	Overprotection/dependency	4.6545	2.518	5.6530	2.268	0.0369*
5	Lack of social support	2.3272	1.414	2.2653	1.642	0.8367
6	Overcommitment/martyrdom	4.3090	1.585	5.0612	1.231	0.0086**
7	Pessimism	2.3454	1.868	3.2040	2.121	0.0304*
8	Lack of family integration	3.1818	2.100	3.6938	2.615	0.2713
9	Limits of family opportunity	1.5090	1.513	2.2857	2.061	0.0329*
10	Financial problems	5.1090	3.189	6.3673	3.967	0.0763
11	Physical incapacitation	2.3454	1.417	3.3265	1.559	0.0011**
12	Lack of activities for index case	1.6545	1.109	1.9183	1.411	0.2893
13	Occupational limitation	1.6545	1.377	2.1836	1.269	0.0451*
14	Social obtrusiveness	0.9818	0.932	1.4489	1.042	0.0176*
15	Difficult personality characteristics	5.6363	2.797	7.3265	4.165	0.0187*

* $p < 0.05$
** $p < 0.01$
*** $p < 0.001$

Significant differences were observed between families with "normal" and "uncertain" expectancies. Subjects in the "uncertain" group scored significantly higher than those in the "normal" group on the following scales: poor mood/health, excess time demands, negative attitude toward index case,

overprotection/dependency, overcommitment/martyrdom, pessimism, limits on family opportunity, physical incapacitation, occupational limitations, social obtrusiveness and difficult personality characteristics.

5.23.3.1 Perceived Life Expectancy and Resources for Management

Student's t-tests were computed to investigate differences in resources between families who perceived normal life expectancy and those with an uncertain prognosis for their children.

Table 74 : Means and standard deviations "normal" and "uncertain" life expectancy and FIRM scores

	Life Expectancy				
	Normal		Uncertain		
N	55		49		
Resource	Mean	SD	Mean	SD	P Value
FS I	35.1090	5.804	32.8163	6.999	0.0709
FS II	38.9818	9.125	35.4081	10.929	0.0722
EFSS	8.8363	2.536	8.6326	2.342	0.6727
FWB	25.7818	10.833	24.1836	11.200	0.4616
SFS	4.3818	1.079	4.2244	1.358	0.5126
SD	14.3454	2.907	12.5102	3.189	0.0027**

** $p < 0.01$

The results indicate that subjects in the "normal" group scored significantly higher than those in the "uncertain" group on the social desirability resource measure (SD).

5.23.3.2 Perceived Life Expectancy and Health-Related Coping Patterns

Student's t-tests were also computed to assess the coping patterns of families who indicated normal and uncertain life expectancies for their children. A missing observation was noted in the uncertain outcome group.

Table 75 : Means and standard deviations of "normal" and "uncertain" life expectancy and CHIP scores

	Life Expectancy				
	Normal		Uncertain		
N	55		48		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	46.5272	7.315	46.2916	7.690	0.8738
CP II	30.6909	8.061	29.3125	9.580	0.7297
CP III	17.6363	4.217	18.2708	3.982	0.4353

In respect of life expectancy, no significant differences in coping patterns were noted.

5.23.3.3 Perceived Life Expectancy and Family Crisis-Oriented Coping Strategies

The results in Table 76 reveal that in respect of life expectancy, there were no significant differences in the family crisis-oriented coping strategies used.

Table 76 : Means and standard deviations of "normal" and "uncertain" life expectancy and F-COPES scores

	Life Expectancy				
	Normal		Uncertain		
N	55		49		
Coping Strategy	Mean	SD	Mean	SD	P Value
ASS	28.2362	7.833	28.714	8.672	0.7684
R	32.9636	4.434	31.2857	5.722	0.0958
SSS	15.3636	4.111	15.2244	4.224	0.8653
MFAAH	11.9336	2.880	12.9591	3.820	0.1343
PA	7.1090	1.068	6.7959	1.743	0.3950

5.23.4 Maternal Education and Stress and Resources

Student's t-tests were used to determine differences in stress and resources, if any, between mothers who have primary and secondary school education.

Table 77 : Means and standard deviations of "primary" and "secondary" school and QRS scores

		Maternal Education				
		Primary School		Secondary School		
N		83		21		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	4.7349	2.996	2.5714	2.181	0.0025**
2	Excess time demands	6.2891	2.615	5.3809	2.060	0.1427
3	Negative attitude toward index case	8.8433	3.493	6.2857	2.532	0.0022**
4	Overprotection/dependency	5.6144	2.299	3.1904	2.040	0.0000***
5	Lack of social support	2.3614	1.574	2.0476	1.283	0.4004
6	Overcommitment/martyrdom	4.8554	1.406	3.9047	1.513	0.0076**
7	Pessimism	2.9518	2.106	1.9523	1.465	0.0430*
8	Lack of family integration	3.6506	2.496	2.5238	1.435	0.0090**
9	Limits of family opportunity	2.0722	1.839	1.0952	1.839	0.0278*
10	Financial problems	6.1445	3.622	3.9523	3.073	0.0123*
11	Physical incapacitation	2.8915	1.607	2.4761	1.327	0.2773
12	Lack of activities for index case	1.8915	1.297	1.3333	1.016	0.0698
13	Occupational limitation	2.0240	1.343	1.4285	1.287	0.0702
14	Social obtrusiveness	1.1686	1.068	1.3333	0.730	0.5065
15	Difficult personality characteristics	6.9277	3.658	4.4761	2.561	0.0047**

* $p < 0.05$
** $p < 0.01$
*** $p < 0.001$

Subjects in the primary school group scored significantly higher than those in the secondary school group on poor mood/health, negative attitude toward index case, overprotection/dependency, overcommitment/martyrdom, pessimism, lack of family integration, limits on family opportunity, financial problems, difficult

personality characteristics scales, and marginally higher on the scale of lack of activities for index case.

5.23.4.1 Maternal Education and Resources for Management

Student's t-tests were used to determine differences in the management of resource between mothers who have a primary and secondary school education.

Table 78 : Means and standard deviations of "primary" and "secondary" school and FIRM scores

	Maternal Education				
	Primary School		Secondary School		
N	83		21		
Resource	Mean	SD	Mean	SD	P Value
FS I	35.5180	6.348	36.0476	6.689	0.1096
FS II	36.7228	10.182	39.5710	9.805	0.2514
EFSS	8.7108	2.442	8.8571	2.475	0.8073
FWB	23.5662	10.879	30.8090	9.589	0.0063**
SFS	4.1927	1.273	4.7660	0.830	0.0165*
SD	13.385	3.153	13.8570	3.260	0.5445

* $p < 0.05$

** $p < 0.01$

Subjects in the secondary school group scored significantly higher than those in the primary school group on the financial well-being (FWB) and sources of financial support (SFS) resource dimensions.

5.23.4.2 Maternal Education and Health-Related Coping Patterns

Student's t-tests were computed to determine differences in health-related coping patterns between mothers who have primary and secondary school education. A missing observation was noted in the primary school group.

Table 79 : Means and standard deviations of "primary" and "secondary" school and CHIP scores

	Maternal Education				
	Primary School		Secondary Sch		
N	82		21		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	45.8414	7.838	48.6666	5.294	0.1219
CP II	30.0121	9.288	30.1904	6.645	0.9344
CP III	17.3658	4.229	20.1428	2.632	0.0005***

*** p < 0.001

Subjects in the secondary school group scored significantly higher than the primary school group on coping pattern III.

5.23.4.3 Maternal Education and Family Crisis-Oriented Coping Strategies

Student's t-tests were used to determine differences in family crisis-oriented coping strategies between mothers who have primary and secondary school education.

Table 80 : Means and standard deviations "primary" and "secondary" school and F-COPES scores

	Maternal Education				
	Primary School		Secondary School		
N	83		21		
Coping Strategy	Mean	SD	Mean	SD	P Value
ASS	28.1686	8.876	29.6190	4.652	0.4718
R	31.9759	5.409	32.9523	3.814	0.4382
SSS	14.9879	4.278	16.5238	3.385	0.1299
MFAAH	12.0240	3.150	14.0476	3.827	0.0135*
PA	6.8313	1.806	7.4761	2.040	0.1577

* $p < 0.05$

Subjects in the secondary school group scored significantly higher than those in the primary school group on the mobilising family to acquire and accept help strategy (MFAAH).

5.23.5 Medical Knowledge and Stress and Resources

The Student's t-tests were computed to examine differences in stress between families who have knowledge of the medical condition of their children and those who do not.

Table 81 : Means and standard deviations of "knowledge" and "no knowledge" and QRS scores

		Medical Knowledge				
		Knowledge		No Knowledge		
N		65		39		
Sc	Stress and Resources	Mean	SD	Mean	SD	P Value
1	Poor health/mood	4.2153	2.907	4.4358	3.110	0.7160
2	Excess time demands	6.1538	2.676	6.0256	2.299	0.8039
3	Negative attitude toward index case	8.2769	3.466	8.4102	3.514	0.8505
4	Overprotection/dependency	4.8000	2.538	5.6666	2.204	0.0703
5	Lack of social support	2.3384	1.481	2.2307	1.597	0.7282
6	Overcommitment/martyrdom	4.6000	1.518	4.7692	1.404	0.5729
7	Pessimism	2.7076	2.126	2.8205	1.876	0.7851
8	Lack of family integration	3.4307	2.499	3.4102	2.136	0.9660
9	Limits of family opportunity	1.9230	1.788	1.7948	1.908	0.7307
10	Financial problems	5.3384	3.671	6.3076	3.480	0.1969
11	Physical incapacitation	2.8307	1.485	2.7692	1.693	0.8465
12	Lack of activities for index case	1.5846	1.157	2.1025	1.372	0.0421*
13	Occupational limitation	2.0153	1.494	1.7179	1.050	0.2780
14	Social obtrusiveness	1.2153	0.976	1.1794	1.072	0.8615
15	Difficult personality characteristics	6.0461	3.252	7.0769	4.061	0.1576

* $p < 0.05$

Subjects in the "no knowledge" group scored significantly higher than those in the "knowledge" group on the lack of activities for index case scale.

5.23.5.1 Medical Knowledge and Resources for Management

The t-test procedure was used to determine whether the management of resources was used differently by families with knowledge of their children's illness and those without.

Table 82 : Means and standard deviations of "knowledge" and "no knowledge" and FIRM scores

	Medical Knowledge				
	Knowledge		No Knowledge		
N	63		39		
Resource	Mean	SD	Mean	SD	P Value
FS I	35.2857	6.994	31.7948	4.995	0.0042**
FS II	38.3015	10.452	35.7435	9.770	0.2144
EFSS	8.8730	2.379	8.4615	2.583	0.4231
FWB	27.5079	10.949	21.1282	10.262	0.0038**
SFS	4.3650	1.067	4.2307	1.459	0.6201
SD	14.0476	3.179	12.5384	3.033	0.0197*

* $p < 0.05$

** $p < 0.01$

Subjects in the "knowledge" group scored significantly higher than those in the "no knowledge" group on the resources of family strength I: esteem and communication (FS I), financial well-being (FWB) and social desirability (SD).

5.23.5.2 Medical Knowledge and Health-Related Coping Patterns

The t-test procedure was also used to assess whether coping patterns were used differently by families with knowledge of their children's illness and those without. A missing observation was recorded in the "no knowledge" group.

Table 83 : Means and standard deviations of "knowledge" and "no knowledge" and CHIP scores

	Medical Knowledge				
	Knowledge		No Knowledge		
N	63		38		
Coping Pattern	Mean	SD	Mean	SD	P Value
CP I	47.1587	7.249	45.1052	7.892	0.1959
CP II	31.2380	8.286	28.1842	9.565	0.1070
CP III	18.5079	3.958	17.0789	4.314	0.1007

No significant differences were noted.

5.23.5.3 Medical Knowledge and Family Crisis-Oriented Coping Strategies

The difference in family crisis-oriented coping as a result of medical knowledge of their children's condition was examined. A missing observation was noted in the "no knowledge" group.

Table 84 : Means and standard deviations of "knowledge" and "no knowledge" and F-COPES scores

	Medical Knowledge				
	Knowledge		No Knowledge		
N	63		38		
Coping Strategy	Mean	SD	Mean	SD	P Value
ASS	28.6349	7.763	28.4615	9.078	0.9214
R	32.3015	5.241	31.8205	5.082	0.6474
SSS	15.3015	4.183	15.6666	3.882	0.6553
MFAAH	13.0476	3.695	11.4102	2.632	0.0106*
PA	6.8412	1.993	7.1538	1.694	0.4001

* $p < 0.05$

Subjects in the "knowledge" group scored significantly higher than those in the "no knowledge" group on the mobilising family to acquire and accept help coping strategy (MFAAH).

5.24 Additional Data Related to Children's Coping Strategies and Self-Esteem

The chi-square and t-test procedures were also used to examine additional variables, and children's coping and self-esteem. The variables examined were

- age of disease onset,
- maternal perception of severity of the child's condition,
- maternal perception of life expectancy of the child,

- maternal education, and
- medical knowledge.

The results are displayed in Tables 85-94.

5.24.1 Age of Disease Onset and Children's Coping Strategies

Chi-square analyses were computed to examine the influence of age of onset of disease in choice of coping strategies. Subjects in the middle childhood onset group scored marginally higher than subjects in the early childhood group on "distraction"; subjects in the early childhood group scored marginally higher than those in the middle onset group on "social withdrawal."

Table 85 : Frequencies and percentages of KIDCOPE responses of early and middle childhood scores

	Age of Onset				
N	Early Childhood (0-4yrs) 44		Middle Childhood (5-12yrs) 61		
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	36	81.82	57	93.44	0.065
Social withdrawal	28	63.64	28	45.90	0.072
Cognitive restructuring	36	81.82	56	91.80	0.125
Self criticism	22	50.00	27	44.26	0.561
Blaming others	6	13.64	9	14.75	0.872
Problem-solving	39	88.64	55	90.16	1.000
Emotional regulation	44	100.00	60	98.36	1.000
Wishful thinking	42	95.45	57	93.44	1.000
Social support	43	97.73	60	98.36	1.000
Resignation	21	47.73	27	44.26	0.725

5.24.2 Age of Disease Onset and Children's Self-Esteem

The t-test was used to determine differences in self-esteem between children with early and middle disease onset.

Table 86 : Means and standard deviations of "What am I like" and early and middle childhood scores

	Age of Onset				
	Early Childhood (0-4yrs)		Middle Childhood (5-12yrs)		
N	44		61		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.7272	0.788	2.9213	0.631	0.1809
Social acceptance	2.7363	0.629	3.0295	0.653	0.0226*
Athletic competence	2.5113	0.578	2.4918	0.709	0.8770
Physical appearance	2.8484	0.645	3.0454	0.609	0.1161
Behavioural conduct	2.9272	0.600	3.0262	0.689	0.4359
Self-worth	2.9280	0.631	3.1967	0.680	0.0400*

* $p < 0.05$

Subjects in the middle childhood disease onset group scored significantly higher than those in the early childhood onset group on the "social competence" and "self-worth" dimensions.

5.24.3 Perception of Severity of Symptoms and Children's Coping Strategies

To compare coping strategies in children who were perceived as having symptoms and those who were not, chi-square analyses were computed.

Table 87 : Frequencies and percentages of KIDCOPE responses and "symptom" and "no symptom" scores

	Severity of Symptoms				
	Symptom		No Symptom		
N	49		56		
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	45	91.84	48	85.71	0.325
Social withdrawal	31	63.27	25	44.64	0.056
Cognitive restructuring	43	87.76	49	87.50	0.968
Self criticism	27	55.10	22	39.29	0.105
Blaming others	7	14.29	8	14.29	1.000
Problem-solving	43	87.76	51	91.07	0.580
Emotional regulation	49	100.00	55	98.21	1.000
Wishful thinking	45	91.84	54	96.43	0.925
Social support	50	98.04	53	98.15	1.000
Resignation	48	97.96	55	98.21	1.000

Subjects in the "symptom" group scored marginally higher than those in the "no symptom" group on "social withdrawal."

5.24.4 Perception of Severity of Symptoms and Children's Self-Esteem

The t-test procedure was used to investigate differences in self-esteem between children with symptoms and those without.

Table 88 : Means and standard deviations of "What am I like" and "symptom" and "no symptom" scores

	Severity of Symptoms				
	Symptom		No Symptom		
N	49		56		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.7877	0.735	2.8857	0.679	0.4823
Social acceptance	2.7265	0.551	3.0642	0.703	0.0070**
Athletic competence	2.4489	0.695	2.5446	0.620	0.4617
Physical appearance	2.9387	0.631	2.9851	0.632	0.7086
Behavioural conduct	2.9469	0.654	3.0178	0.655	0.5810
Self-worth	3.0102	0.623	3.1488	0.708	0.2889

** $p < 0.01$

Subjects in the "no symptom" group scored significantly higher than those in the "symptom" group on the "social competence" dimension.

5.24.5 Perceived Life Expectancy and Children's Coping Strategies

Chi-square analyses were conducted to determine differences in coping between children who were perceived to have normal life expectancy and those with an uncertain prognosis.

Table 89 : Frequencies and percentages of KIDCOPE responses and "normal" and "uncertain" life expectancy scores

	Life Expectancy				
	Normal		Uncertain		
N	54		51		
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	48	88.89	45	88.24	0.916
Social withdrawal	26	48.15	30	58.82	0.273
Cognitive restructuring	49	87.50	43	87.76	0.968
Self criticism	24	44.44	25	49.02	0.639
Blaming others	9	16.07	6	11.76	0.473
Problem-solving	51	94.44	43	84.31	0.090
Emotional regulation	53	98.15	51	100.00	1.000
Wishful thinking	51	94.44	48	94.12	1.000
Social support	53	98.15	50	98.04	0.738
Resignation	20	37.04	28	55.90	0.066

Subjects in the "uncertain" group scored marginally higher than those in the "normal" group on the "resignation" coping strategy.

5.24.6 Perceived Life Expectancy and Children's Self-Esteem

The t-test procedure was used to investigate the self-esteem of children whose families perceived them to have "normal" life expectancies and those who were perceived to have "uncertain" life expectancies.

Table 90 : Means and standard deviations of "What I am like" and "normal" and "uncertain" life expectancy scores

	Life Expectancy				
	Normal		Uncertain		
N	54		51		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.9555	0.714	2.7176	0.679	0.0833
Social acceptance	3.0074	0.627	2.8000	0.675	0.1067
Athletic competence	2.5864	0.624	2.4084	0.680	0.1666
Physical appearance	2.9413	0.689	2.9869	0.565	0.7112
Behavioural conduct	3.0481	0.603	2.9176	0.701	0.3103
Self-worth	3.1080	0.712	3.0588	0.629	0.7081

No significant differences were observed between the self-esteem of subjects in the "normal" and "uncertain" groups.

5.24.7 Maternal Education and Children's Coping Strategies

Chi-square analyses were computed to examine differences in coping between children whose mothers had primary and secondary school education.

Table 91 : Frequencies and percentages of KIDCOPE responses and "primary" and "secondary" school scores

	Maternal Education				
	Primary School		Secondary School		
N	51		46		
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	75	88.24	17	77.27	0.187
Social withdrawal	44	51.76	10	45.45	0.598
Cognitive restructuring	73	85.88	19	86.36	1.000
Self criticism	42	49.41	8	36.36	0.274
Blaming others	13	15.29	2	9.09	0.361
Problem-solving	75	88.24	18	81.82	0.480
Emotional regulation	82	96.47	21	95.45	1.000
Wishful thinking	79	92.94	20	90.91	0.667
Social support	81	95.29	21	95.45	1.000
Resignation	37	43.53	9	40.91	0.825

No significant differences were noted.

5.24.8 Maternal Education and Children's Self-Esteem

The t-test was used to examine the self-esteem of children whose mothers had primary and secondary school education.

Table 92 : Means and standard deviations of "What am I like" and "primary" and "secondary" school scores

	Maternal Expectancy				
	Primary School		Secondary School		
N	51		46		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8823	0.719	2.7130	0.671	0.2335
Social acceptance	2.8823	0.637	2.9260	0.668	0.7430
Athletic competence	2.5849	0.672	2.3949	0.660	0.1640
Physical appearance	3.0653	0.542	2.8586	0.663	0.0990
Behavioural conduct	3.0274	0.642	2.9521	0.662	0.5723
Self-worth	3.1176	0.649	2.9891	0.685	0.3468

No significant differences were observed.

5.24.9 Medical Knowledge and Children's Coping Strategies

Chi-square analyses were computed to determine differences in coping strategies used by children from families who have medical knowledge of their illness and those whose families lacked such knowledge.

Table 93 : Means and standard deviations of KIDCOPE responses and "knowledge" and "no knowledge" scores

	Medical Knowledge				
	Knowledge		No Knowledge		
N	66		39		
Coping	Freq	Percent	Freq	Percent	P Value
Distraction	57	88.36	36	92.31	0.528
Social withdrawal	36	54.55	20	51.28	0.746
Cognitive restructuring	57	86.36	35	89.74	0.763
Self criticism	28	42.42	21	53.85	0.257
Blaming others	10	15.15	5	12.82	0.742
Problem-solving	60	90.91	34	87.18	0.532
Emotional regulation	66	100.00	38	97.44	0.371
Wishful thinking	62	93.94	37	94.87	1.000
Social support	64	96.97	39	100.00	0.529
Resignation	31	46.97	17	43.59	0.737

No significant differences were noted.

5.24.10 Medical Knowledge and Children's Self-Esteem

The t-test procedure was used to investigate the self-esteem of children from families who had knowledge of the medical condition and those who had not.

Table 94 : Means and standard deviations of "What I am like" and "knowledge" and "no knowledge" scores

	Medical Knowledge				
	Knowledge		No Knowledge		
N	66		39		
Self-Esteem	Mean	SD	Mean	SD	P Value
Scholastic competence	2.8363	0.665	2.8461	0.795	0.9483
Social acceptance	2.9212	0.641	2.8820	0.687	0.7735
Athletic competence	2.5497	0.622	2.4188	0.708	0.3484
Physical appearance	2.9494	0.597	2.9871	0.687	0.7768
Behavioural conduct	2.9363	0.672	3.0666	0.617	0.3152
Self-worth	3.0328	0.637	3.1709	0.722	0.3268

No significant differences were noted.

5.25 Normative Data Derived from the Present Study

To the author's knowledge, the present investigation represents the first application of resiliency measures (that is, FILE, FIRM, CHIP, and F-COPES) and the Questionnaire on Resources and Stress (QRS) within a South African Indian population. It was

considered valuable to establish normative data for future research with this population. To accomplish this, mean and standard deviations were computed on the scores of the control group of families (that is, female adult respondents) of non chronically ill children (control group).

5.25.1 Normative Data on the Resiliency Measures (FILE, FIRM, CHIP, and F-COPES)

The data below reflects the mean and standard deviations of each of the resiliency measures. The upper and lower limits of the range for the control sample is provided.

N		30	Range	
	Mean	SD	Lower limit	Upper Limit
FILE				
Total Scale	8.566	4.643	0	22.13
FIRM				
FS I	33.033	3.782	25.47	40.59
FS II	38.200	7.553	23.10	53.30
EFSS	8.800	2.469	3.86	13.74
FWB	23.400	10.223	2.96	43.84
SFS	4.333	0.841	2.65	6.01
SD	13.333	3.122	7.09	19.57
Total Scale	107.966	18.758	70.45	149.83
CHIP				
CP I	45.766	7.444	30.90	60.70
CP II	30.566	8.479	13.61	47.00
CP III	16.633	3.547	9.53	23.70
F-COPES				
ASS	28.266	6.822	14.63	41.91
MFAAH	11.733	2.531	6.67	16.79
PA	7.000	1.681	3.64	03.64
R	31.966	4.972	22.03	41.91
SSS	14.800	4.574	5.66	23.94

The normative data for most the scales contained in the resiliency measures fall within the normal or moderate ranges of the original normative data (based on an American population) (McCubbin and Thompson 1991).

With exception, the mean norm score proposed for FILE fell a point below the original normative range. This may indicate that South African Indian mothers have a higher threshold for life events and changes and therefore exhibit a point lower than the range.

The proposed normative mean data for the scales comprising the FIRM (that is, Family Strength I, Family Strength II, Extended Family Social Support, Financial Well-being, Social Desirability), and the total FIRM scale, fall within the range similar to most of the American families in the original normative study, indicating moderate resource levels (McCubbin and Thompson 1991).

The suggested normative mean for all three coping patterns of the CHIP fall within the normal range, and are similar to the American Study (McCubbin and Thompson 1991).

The mean F-COPES scores for all five scales fall within the normal range for adult females (McCubbin and Thompson 1991).

5.25.2 Normative Data on the Questionnaire on Resources and Stress (QRS)

Normative data is provided on the 15 scales of the QRS, based on the control sample, for use with a South African Indian population.

The upper and lower limits of the range for the control sample are displayed below.

N		30		Range	
QRS		Mean	SD	Lower Limit	Upper Limit
Sc 1	Poor health/mood	3.233	2.514	1.797	8.263
Sc 2	Excess time demands	4.766	2.062	0.641	8.893
Sc 3	Negative attitude toward index case	7.400	2.883	1.632	13.16
Sc 4	Overprotection/dependency	4.733	2.333	0.067	9.399
Sc 5	Lack of social support	1.900	1.184	0.47	4.27
Sc 6	Overcommitment/martyrdom	4.333	1.647	1.039	7.624
Sc 7	Pessimism	2.633	1.564	0.495	5.761
Sc 8	Lack of family integration	2.733	2.083	1.433	6.899
Sc 9	Limits of family opportunity	1.266	1.337	1.407	3.940
Sc 10	Financial problems	4.933	2.651	0.369	10.23
Sc 11	Physical incapacitation	2.233	1.478	0.723	5.189
Sc 12	Lack of activities for index case	1.633	1.188	0.744	4.01
Sc 13	Occupational limitation	1.500	1.042	0.584	3.584
Sc 14	Social obtrusiveness	0.966	0.927	0.889	2.822
Sc 15	Difficult personality characteristics	5.566	3.002	0.437	11.571

The Indian South African normative range for 15 QRS scales falls within the normative percentile range for control families of school-aged children (Holroyd, 1987).

5.25.3 Normative Data on The Self-Perception Profile for Children ("What I am like")

Normative data have been derived for the South African Indian population, based on the total control sample of normal children (males and females). The mean, standard deviation and upper and lower limits of the ranges are depicted below. A comparison with the American normative data is not possible, as the present sample comprises too few boys to enable comparison by gender.

	Control			
N	30		Range	
Self-Esteem	Mean	SD	Lower Limit	Upper Limit
Scholastic competence	3.040	0.663	1.714	4.366
Social acceptance	3.293	0.484	2.32	4.256
Athletic competence	2.488	0.719	1.05	3.926
Physical appearance	3.094	0.576	1.94	4.24
Behavioural conduct	3.386	0.535	2.32	4.457
Self-worth	3.350	0.679	1.99	4.71

5.26. Summary of Results

- Significantly more leukaemic families sought assistance from a priest and had knowledge of the medical condition (cf. 5.2).
- Mothers of asthmatic children were significantly older than mothers of control and leukaemic children. The families of children with nephrotic syndrome and leukaemia had significantly higher incomes than families of asthmatic and control children (cf. 5.3).
- There were no significant differences among the four groups of families in life events and changes. There were significant differences in the stress experienced by the four groups of families, in the resources used by the four groups of families, among the four groups in their use of health-related coping patterns, in the family crisis-oriented coping patterns used by the four groups (cf. 5.3).
- There were no significant differences between the asthmatic and control, leukaemic and control, and nephrotic syndrome and control groups in family life events and changes (cf. 5.4.1).
- The asthmatic, nephrotic syndrome and leukaemic groups experienced significantly more stress than the control group (cf. 5.4.2).
- There were no significant differences between the asthmatic and control groups in the use of resources. However, significant differences were observed between the nephrotic syndrome and control groups, and the leukaemic and control groups, on the "financial well-being" resource. There were also significant differences between the nephrotic syndrome and the control group on the "family strength I : esteem and communication" resource dimension (cf. 5.4.3).
- There were no significant differences between the asthmatic and control groups in the use of health-related

coping patterns. Both the leukaemic and nephrotic syndrome groups utilised coping pattern III significantly more than the control group (cf. 5.4.4).

- There were no significant differences between the asthmatic and control groups in the use of family crisis-oriented coping patterns. The nephrotic group utilised the "seeking social support" and "mobilising family to acquire and accept help" coping strategies significantly more than the control group (cf. 5.4.5).
- The chronically ill group sought assistance from a priest, had medical knowledge and indicated a poorer prognosis (life expectancy) for their children significantly more than the control group. Significantly more males than females had chronic illness (cf. 5.5; cf. 5.12).
- There were no significant differences between the chronically ill and control groups in family life events and changes. However, the chronically ill group experienced significantly more stress than the control group. There were no significant differences in the resources used by the two groups. There were significant differences between the two groups in health-related coping patterns, with the chronically ill group utilising coping pattern III significantly more than the control group. There were no significant differences between the two groups in family crisis-oriented coping (cf. 5.5).
- Children and mothers in the remission sub-group had significantly higher ages than those in the induction sub-group. The induction sub-group experienced significantly more stress than the remission sub-group. There were no significant differences between the two sub-groups in respect of resources, health-related coping patterns or family crisis-oriented coping strategies (cf. 5.6).
- Families experienced significantly more stress in respect of males than females. There were significant differences between families' responses to the "passive appraisal" coping strategy, and a marginal difference in the response

to the "mobilising family to acquire and accept help" coping strategy, in respect of girls (cf. 5.7).

- There were significant negative associations between certain stressors, and resources and coping patterns (cf. 5.8).
- Significantly more asthmatic and nephrotic children were males. Leukaemic children had significantly fewer peer relationships than the other groups of children (cf. 5.9).
- There were no significant differences between asthmatic and control children in their use of coping strategies. The control children used the "distraction" coping strategy significantly more than the nephrotic children and marginally more than leukaemic children. The leukaemic children used the "social withdrawal" coping strategy significantly more than the control group (cf. 5.11).
- The control group of children utilised the "distraction" coping strategy significantly more than the chronically ill group. The chronically ill group used the "social withdrawal" strategy significantly more than the control group (cf. 5.12.1).
- There were no significant differences between children in the remission and induction sub-groups in their use of coping strategies (cf. 5.13).
- There were no significant differences between boys and girls in their use of coping strategies (cf. 5.14).
- Certain coping strategies used by children were associated with health-related and family coping and resource dimensions (cf. 5.15).
- The control group have significantly higher perceptions of "social competence" and "behavioural conduct" than asthmatic, leukaemic and nephrotic syndrome children, a higher perception of "scholastic competence" than asthmatics and leukaemic children, and higher "self-worth" than leukaemic children (cf. 5.16).
- The control group displayed significantly higher self-esteem on certain dimensions, than chronically

ill children (cf. 5.17).

- Children in the induction sub-group had a significantly higher self-perception in respect of "behavioural conduct" than children in the remission sub-group (cf. 5.18).
- Females had significantly higher self-perception in respect of "scholastic competence" and "behavioural conduct" than males (cf. 5.19).
- Certain self-esteem dimensions were associated with children's coping strategies (cf. 5.20).
- There were significant associations between certain self-esteem dimensions and self-worth (cf. 5.21).
- There were weak associations between self-esteem dimensions, and health and family coping and resources (cf. 5.22).

Additional Data (cf. 5.23).

- There were no significant differences in the stress profiles of families in the early and middle childhood onset groups. However, the early childhood onset group used "family strength I: esteem and communication" and the "extended family social support" resources significantly more than the middle childhood onset group. The early childhood onset group also used coping patterns I and III significantly more than the middle childhood onset group. There were no significant differences in respect of family-crisis oriented coping strategies.
- Families in the "symptom" group experienced significantly more stress than those in the "no symptom" group. The "no symptom" group used the "family strength I: esteem and communication resource" and coping pattern I significantly more than the "symptom" group. No significant differences were noted between the two groups in respect of family crisis-oriented coping strategies.
- Families in the uncertain life expectancy group experienced significantly higher stress profiles than those in the normal life expectancy group. The normal expectancy group utilised the "social desirability"

resource significantly more than the uncertain group.

- Mothers in the primary school group experienced significantly more stress than those in the secondary school group. The secondary school group used the "financial well-being" and "sources of financial support" resources, coping pattern III, and "mobilising family to acquire and accept help" coping strategy significantly more than the primary school group.
- Subjects with no medical knowledge experienced significantly higher stress on the "lack of activities" scale. Subjects with medical knowledge used the "family strength I: esteem and communication," "financial well being" and "social desirability" resources, and "mobilising family to acquire and accept help" coping strategy significantly more than subjects with no medical knowledge.

Additional Data (See 5.24).

- Children in the middle childhood onset groups utilised "distraction" marginally more than those in the early childhood onset group. Children in the early childhood onset groups utilised the "social withdrawal" coping strategy more than the middle childhood onset group.
- Children in the "symptom" group utilised "social withdrawal" coping strategy marginally more than children in the "no symptom" group. Children in the "no symptom" group scored significantly higher on "social competence" than those in the "symptom" group.
- Children in the uncertain life expectancy group utilised the "resignation" coping strategy marginally more than children in the normal life expectancy group.
- There were no significant differences in the coping strategies and self-esteem of children in respect of mothers' educational level or medical knowledge.
- Normative data on the resiliency measures, QRS and Self-Perception Profile for Children were derived from the South African Indian population.

CHAPTER SIX

DISCUSSION

6.1 Introduction

While there have been many studies investigating the impact of chronic childhood illness, few have explored the range of adaptation in families of asthmatic, leukaemic and nephrotic children. Even less is known about the stressors experienced when raising a chronically ill child. The present study has addressed a series of questions regarding the stressors experienced, the styles of coping, and accessible resources which contribute to the psychological adaptation of families of young children with chronic illness. Parental styles of coping and the resources used have also been examined. Furthermore, given the lack of empirical information on the resiliency model, the study explored this aspect. The study also focused on children's coping strategies and their self-perception of competence, esteem and self-worth. The responses of a control group of non chronically ill children and their mothers were compared with those of the ill group subjects and their mothers in this study. The study also provides normative data.

The statistical analysis described in the previous chapter produced significant results, many of which supported the hypotheses proposed in this study. This chapter discusses the findings of the research.

6.2 Stress and Adaptation: A Comparison of the Families of Children with Specific Illnesses and the Control Group

As hypothesised, the illness groups displayed significantly higher levels of stress than the control group. This is consistent with the findings of other researchers (Holroyd 1987, Holroyd and Guthrie 1986, Walker et al. 1992) who note that different illness groups are likely to present with different patterns of stress. As noted in the review of literature, few studies have focused on the stress profiles of the specific conditions selected for this study. Comparisons with other studies are, therefore, not always possible.

6.2.1 A Comparison of the Families of Asthmatic and Control Children

Mothers of asthmatic children presented with a stress profile which differs significantly from that of the control group, thereby supporting hypotheses 2a.

6.2.1.1 Personal problems scales

Families in the asthmatic group scored significantly higher than the control group on the following personal stress scales: "poor mood/health," "excess time demands," "negative attitude toward index case," and "overprotection/dependency."

The finding that mothers of asthmatic children experienced a pervasive sadness, tension, fatigue, and dissatisfaction with their lives suggests possible depressive features. The "poor mood/health" was characteristic only of mothers of asthmatic

children and was not displayed by mothers in the other illness groups or the control group.

A combination of factors may contribute to this finding. One may be the characteristics of asthma, which frequently requires vigilant night-time care (Travis 1976); this may cause distress, particularly if the attacks persist over months. An additional burden for the mother of the asthmatic is the effort to keep the home dust-free (Eiser 1990). This may contribute to the finding of high "excess time demands" among these mothers in comparison with mothers in the control group.

The finding of "poor health/mood" on the part of the mother concurs with other research (Frank et al. 1991), and supports the theoretical viewpoint that certain families of ill children may be at risk for maladjustment which relates to the special demands and stressful experiences to which they are exposed (Kazak and Marvin 1984, Varni and Wallender 1989, Walker et al. 1989, Walker et al. 1992).

The high "excess time demands" result was also characteristic of the mothers of children with leukaemia and nephrotic syndrome, indicating that mothers of chronically ill children generally experience stress in this area.

Mothers of asthmatic children also tend to display a "negative attitude" toward their children, perhaps attributing their dissatisfaction and stress to the child. Such feelings may give rise to resentment and guilt on the part of the parents, with resultant over-compensation toward the child. However, as the "negative attitude toward index case" scale also measures the sensitivity to what others might think about them and their child, mothers of asthmatic children may be extremely concerned about their children's

lives.

The fact that members of this group more than either of the two illness groups live in an extended (56.67%) rather than a nuclear (43.33%) family system may also account for their high level of personal and family stress (detailed below). The mother may wish for independence and privacy, which may not always be possible, particularly in a poorer home with less personal space.

As many families of asthmatic children were found to reside with the paternal family (30%), the expectation of the traditional Indian household would be that the daughter-in-law assumes responsibility for the household chores. Hence, the mother's attitude and fatigue may also be related to the increased emotional and physical stress experienced.

In an analysis of women's family roles, Baruch et al. (1987) argue that women are particularly vulnerable to stress because their roles in the family often combine a high level of psychological demands with a low level of control. This situation is true for mothers who are responsible for the well-being of children with illnesses such as asthma that have unpredictable and uncontrollable effects on the child. For some women, a balance of psychological demands and control could be more readily attained in the workplace than at home. Consequently, employment may serve as a buffer against the stress arising from the family roles. Several studies have indicated higher levels of emotional and physical well-being among women who occupy the three roles of wife, mother, and employee compared to women who occupy fewer roles (Thoits 1986, Pietromonaco et al. 1986). In the case of mothers of children with chronic disorders, employment may provide both temporary relief from caretaking concerns and

the opportunity for self-expression and achievement in another realm (Walker et al. 1989). Employment of the mother has also been found to mitigate the relationship between maternal depression and reported child psychological problems (Ghodsian et al. 1984). Again, these factors may be particularly beneficial to mothers of asthmatic children.

However, a point of consideration is the work role characteristics related to work/family conflict: namely, work load pressure and hours, particularly with lower income families or families experiencing financial pressure. These factors indicate high levels of energy demands and time at work at the cost of family life, apart from the strain of having an ill child. Therefore, it seems likely that the mother's mental health may be affected by social problems rather than by the condition of her child.

The relatively greater age of asthmatic mothers in comparison with mothers in the leukaemic and control groups may also add to the difficulty experienced in rearing a chronically ill child. This finding, to an extent, is supported by Holroyd and others (1975) and Murphy (1980) who found that older mothers of autistic children and children with birth defects also reported more stress. However, there were no differences in the ages of mothers of nephrotic and control children, the former also reporting less stress. This suggests that the age of the parents may not be a conclusive factor in experiencing the stress of chronic childhood illness.

A contributory factor to the high stress profile experienced by this group is the finding that many mothers had only achieved a primary school education (86.67%) rather than a secondary education (13.00%). Mothers with a lower level of

education were found to experience significantly more stress than mothers who had received secondary school education. Hence, mothers of asthmatic children in this sample may be at risk for an increased level of stress unless therapeutic and psychosocial intervention is offered.

A further factor which emerged from the interviews with many mothers of asthmatic children is the poor support received from, and the difficulty they experienced in communicating with health personnel, particularly the doctors treating their children. This may also contribute to uncertainty about the outcome of the disease, which in itself is frustrating. As the families of children with leukaemia and nephrotic syndrome have commented on the support received from their health professionals, and have displayed certain competencies (cf. 6.4.3; 6.4.4), it is likely that the perception of a poor relationship with the doctor is an additional contributory factor to the stress experienced by mothers of asthmatic children.

6.2.1.2 Family problems scales

The asthmatic group scored significantly higher than the control group on the family stress scales of "lack of family integration," "limits on family opportunity," "financial problems" and "negative attitude toward index case."

These areas of stress experienced by mothers of asthmatic children may be due to several reasons. It is highly probable that the child may not be integrated as much into family activities due to anxieties and fears about his illness. Another explanation may be the difficulty experienced in living within the extended family system, and

the perception of a lack of support from other members by the mother of the ill child. Family disharmony and a possibly unsupportive environment may be stressful for any child, and even more so for the asthmatic child whose attacks may be induced by emotional factors. These findings are consistent with those of Peri et al. (1991) and Brook and Shemesh (1991). Other researchers refer to the variable range of family functioning as a result of the experience of different illnesses, but with indications of a higher level of maternal distress (Tavormina et al. 1977, Kazak 1987).

Of particular relevance are the varying degrees of disruption of family routines caused by childhood asthma, such as unscheduled emergency room visits and hospitalisation. The parent who must make periodic trips to hospital must rely on practical assistance (for example, the care of other children) as well as emotional support. The mother of the asthmatic child may need more support because of these demands, which may sometimes increase without her needs being met. Thus, the support or need required by the mother of an asthmatic child may vary considerably from the mother with a healthy child. While both families may have the same number of supportive relationships, the adequacy or perceived satisfaction with support provided by these relationships may differ (Hamlett et al. 1992). This is critical for all families of chronically ill children, with the possible resultant perceptions of lack of intra-familial support. Families who have difficulty sharing their problems would experience demoralisation unless intervention and support is made available (Venters 1981).

In many traditional Indian homes, household and child-care duties are believed to be the responsibility of the woman. The father is less likely to involve himself with these functions and may often be the silent and emotionally absent

partner. If the father helped (for example in the administration of medication at night) it would not be done at the expense of his regular activities. These findings are supported by Frank et al. (1991) in reference to mid-western American men, parenting alliance and childhood illness. It follows that such mothers would be more likely to perceive their duties as further burdens, and with the added experience of financial stress have a more negative perception of family life overall. In this context, Trivette and Dunst (1988) have found that mothers who are comfortable with the household and child care responsibilities appear to be less distressed.

The families of asthmatic children scored significantly higher than the three other groups on financial problems, reflecting a lower income level and financial burden. Families of asthmatics appear to have more problems with housing and accommodation, as well as medical and related costs incurred in caring for an asthmatic child. Such findings illustrate the economic pressures faced by this group which may exacerbate the personal and family stress experienced. Furthermore, since many of the mothers of asthmatic children are not employed outside the home, it is likely that the family income was not supplemented.

The lower socio-economic status also means that the already burdened mother would not be able to hire help as would mothers of a relatively higher income bracket. It should be noted, however, that this dimension of financial problems may be characteristic of the sample, and may not be true of all families of asthmatic children.

These findings corroborate the view of Wallender et al. (1989) who point to difficulty in family adjustment when financial resources are meagre, when family conflicts exist and when the family is disorganised or does not work together.

6.2.1.3 Problems of index case scales

The asthmatic group scored significantly higher than the nephrotic, leukaemic and control subjects on the "overprotection/dependency" scale. Mothers of asthmatic children were more protective than mothers in the other three groups and perceived their children to be more dependent. In this context, there may be some basis in the view postulated decades ago that asthma in children is associated with disturbance in the mother-child relationship, and with conflict over achieving independence from the mother (Freeman et al. 1964). Roth (1961) explained over-protection as being the prevention of the development of independent behaviour, and excess control by the mother over the child, in terms of maternal anxiety, which becomes a defense against hostility or guilt of rejection. Similarly, children who perceive their families as controlling report greater feelings of hostility and anger (Farber et al. 1985).

The over-protection may be due to a realistic concern on the part of the mother (Creer et al. 1988), since asthmatic children tend to be allergic to many different substances. There is also the frustration of recognising that one is incapable of controlling the environmental factors which seem to affect the illness. Anxiety on the part of the family, particularly in the absence of medical information and psychological assistance (Brook and Shemesh 1991), may further induce over-protective behaviour. It is likely that

these responses, while seemingly maladaptive, may in fact be adaptive considering the nature of the illness.

However, researchers point to such restrictive responses as having a negative effect on the capacity of the child and his family to cope and to adjust, thus reinforcing the dependency (Creer 1979, Drotar et al. 1984). For instance, mothers of asthmatic children may reinforce dependency in their children by being protective toward them. This may be characteristic of Indian mothers who tend to be particularly over-protective of their children, who are likewise dependent upon their parents even as they grow older. Similar findings were revealed in a Japanese sample (Kodaki and Inanami 1978b).

Furthermore, mothers of asthmatics who live in extended family systems may tend to be over-protective or over-indulgent in an attempt to assert their authority, since grandparents are likely to take over the major part of the child-rearing responsibilities and may even oppose the parent's suggestions. Eiser et al. (1992) have also suggested that mothers may feel comfortable with the increased dependency which the disease imposes on children, and may perceive their children as remaining dependent longer than healthy children. These reactions, although viewed as maladaptive, may function to maintain a protective homeostasis for the family. Therefore, intervention should attempt to establish an equilibrium that would be more conducive to the healthy functioning of all the members of the family system (Kazak 1989).

The over-protection may not only prevent the child from developing adequately in the physical and sporting areas, but from developing the necessary skills to cope with the illness effectively.

The mothers in all three illness groups scored significantly higher than those in the control group on the "physical incapacitation" scale. This suggests that mothers in the illness groups perceived the health status and self-help functioning of their children as being poor. They also perceived their ill children as not being able to take part in normal sporting activities and outings. While this finding may be due to the nature of the illness, it may also be due to the perceptions of over-protective or depressed mothers (such as the mothers of asthmatic children) or the anxiety involved in being a parent of an ill child (Carswell et al. 1990).

These findings are consistent with other studies (Kazak et al. 1988, Hamlett et al. 1992) and suggest that families of asthmatic children may be at higher risk for intra-familial problems, enmeshed mother-child relationships, maternal depression, and poor adaptation.

6.2.2 A Comparison of the Families of Leukaemic and Control Children

The leukaemic sample scored significantly higher than the control group on only two of the fifteen QRS scales.

As hypothesised, families of leukaemic children experienced more stress than the control group. Mothers of leukaemic children scored significantly higher on the "excess time demands" scale than families of healthy children. This reflects a perception of greater time and responsibility allocated by mothers to children with leukaemia. These findings are consistent with other research on families of children with cancer (Spinetta 1982, Friedman and Mulhern

1992).

Families of children with leukaemia also scored significantly higher than the control group on the "physical incapacitation" scale. This perception may be due to the periods of acute illness in the child's life when the adequacy of physical functioning is affected. As indicated in the review of literature, leukaemia is an extremely distressing condition. Therefore, such families may possibly have responded with realistic concern.

While these results are consistent with the views of other researchers (Matinssou and Cohen 1988, Barbarin 1990), they indicate that the traumatic experience of childhood leukaemia may not necessarily increase the level of stressors for all families. As even minor childhood illness can be a significant source of stress for mothers (Carey and Sibinga 1972), it may be assumed that the families of children suffering from leukaemia (an illness contributing to many stresses) may have a certain resiliency and competency to reduce the strains and stressors associated with the illness.

6.2.3 A Comparison of the Families of Nephrotic Syndrome and Control Children

In terms of identifying stressful areas for families of nephrotic syndrome children as compared to the control sample, two areas of stress were identified. These were "excess time demands" and "occupational limitation for index case," which were significantly higher for the families in the nephrotic group.

The mothers of nephrotic children, like mothers of the other two illness groups, perceive the condition of nephrotic syndrome as placing excessive demands on their time. In this context, Sabbeth (1984) noted that it is not only the parental time but the emotional energy directed to the child with chronic illness that should be considered. The increasing age of the child does not seem to release the mother from this responsibility (Holroyd 1987).

The families of children with nephrotic syndrome also perceive their children's opportunities for education and training as being compromised, and worry about their future. Such a perception may be due to the anxiety of having a seriously ill child. Similar concerns were found in parents of children with cancer (Koocher and O'Malley 1981). However, as this group is relatively financially secure, it may be that the families are also more sophisticated, and, therefore, express concern about their children's educational and career prospects. Kupst and Schulman (1988) have indicated that families with higher incomes have more resources and are also higher functioning.

6.2.4 Conclusion

As can be seen from the above discussion, the variation in the stress profiles of illness groups across the study samples may account for the different findings discussed in the review of literature on the impact of the child's chronic condition on the family. It is evident that the specific disease categories of asthma, leukaemia and nephrotic syndrome are associated with stressors, some common to all three conditions.

The findings of the present study reaffirm that family adaptation to certain chronic paediatric conditions must be considered in relation to the nature and characteristics of stress that differentiate these conditions. This is consistent with the conclusions of many researchers (Holroyd and Guthrie 1986, Eiser 1990, Barden 1991, Walker et al. 1992) and supports the view that chronic illnesses should not be grouped together but should be viewed independently in psychological study (Varni and Wallender 1988, Wallender et al. 1989, Dolgin et al. 1990, Mullins et al. 1991).

The results emphasise that chronic illness be considered within a familial and societal context (Stanton 1980). Hence, interventions designed to enhance adaptation should be tailored to address needs that vary with the particular type of childhood impairment and with individual competencies of each family system.

6.3 Stress, Coping and Adaptation: A Comparison of the Families of Chronically Ill and Control Children

Notwithstanding the above comments, an assessment was conducted to examine differences in the stress experienced between families of chronically ill children (that is, all three illness groups combined) in comparison with families of non chronically ill or healthy (control) children.

6.3.1 Personal and family problems scales

The chronically ill group scored significantly higher than the control group on personal and family stress scales of

"poor mood/health," on "excess time demands," and "lack of family integration."

These findings illustrate that families having children with chronic illness perceive higher levels of stress in three areas, thereby supporting hypothesis 7. The experience of chronic illness in the family, particularly in the young child, may be related to the poorer mood and ill health of the mother. As all children who are ill require additional care, the time allocated to a chronically ill child would be all the more consuming and demanding, both physically and emotionally. These findings could also be understood in relation to the developmental age of the child. The younger child with which this research is concerned, would require and demand more parental care-giving and assistance. The experience of chronic illness may additionally contribute to a developmental delay or to regression in the anxious and troubled child (Barbarin 1990), and may increase his dependency on the care-giver. The lack of family integration also appears characteristic of families experiencing chronic illness. This may be due to other family members perceiving the mother as being too involved in the care of the ill child and duties of the family. At the same time, the father and siblings may be perceived by the mother as unsupportive and uncaring.

The results of the present study are consistent with other studies (Holroyd and Guthrie 1979, Garmezy et al. 1984, Bendell et al. 1986, Holroyd and Guthrie 1986, Daniels et al. 1987, Frank et al. 1991) and with the interpretation of childhood chronic illness as a chronic stressor that may affect family systems (Hamlett et al. 1992).

The finding that mothers of chronically ill children experience more personal and family stress is consistent with those of other researchers (Barbarin et al. 1985, Phillips et al. 1985). The atmosphere of intra-familial tension could have negative consequences for the ill child's self-image and coping. These experiences may be regarded as common to the experience of chronic illness, but with the appropriate psychosocial intervention may not necessarily foster maladaptation in the ill child (Drotar et al. 1984, Bull and Drotar 1991).

6.3.2 Problems of index case scales

The chronically ill group scored significantly higher than the control group on the "physical incapacitation" scale. Thus, chronically ill children are perceived by their mothers as having being compromised with respect to physical and self-help functioning. This perception appears to be characteristic of families who have seriously ill children, whose functioning may be affected periodically. However, such a perception may have implications for the child's efforts to master his normal developmental tasks and biobehavioural agenda (Garrison and McQuiston 1989), and implies that chronic illness interferes with mastery and disturbs the equilibrium of development of the most common tasks of childhood as well as the child's self-esteem and coping skills.

The chronically ill group scored significantly higher than the control group on the "occupational limitations for index case" scale. Families were concerned about the limitations the illness would impose on the educational, occupational and personal growth of their chronically ill children. These feelings may be understandable in view of the parent's

anxiety and possible fear of the future prospects of their children as well as their own future. Similar emotions were found in the parents of children with cancer (Koocher and O'Mally 1981) and may hold true for most parents who have children with serious and/or handicapping conditions. Holroyd (1987) has stated that it is the severity of illness at the time of assessment rather than the prognosis (for lifetime disability or death) which exacerbates this concern.

The present findings lead to a better understanding of the problems perceived by families experiencing chronic childhood conditions. It is noteworthy that it is the pattern of stress, rather than simply an increased level of stress that differentiates the chronically ill group from the control group. The characteristics of family stress described clearly indicate that chronic illness may increase the risk of negative psychological adaptation for the family of the ill child, but may not be the sole source of dysfunction (Pless et al. 1972). The stress profile of families experiencing chronic childhood illness should, therefore, be examined with a view to appropriate intervention.

6.4 The Resiliency Model and Chronic Childhood Illness

In order to describe or predict how families adapt in a chronic stress situation, the resiliency model requires an assessment of the cumulative family life changes or pile-up of demands of stressors which are associated with a decline in family functioning and with negative correlates in individual members. Such demands may contribute to interaction with a medical condition or treatment and may render the family incapable of responding in a constructive manner to the needs of the chronically ill child.

Furthermore, the resiliency model incorporates information on the coping behaviours and resources utilised by families. It was hypothesised that families possessing a larger repertoire of coping behaviours and resources will manage more effectively and will adapt to the stress of chronic illness.

To the author's knowledge there have been very few studies based on this model. Comparisons, therefore, may not always be possible.

6.4.1 Family Life Events and Changes

The finding that there were no significant differences in the "pile-up" of stressful life events and changes among the four groups (asthma, leukaemia, nephrotic syndrome and control) suggests that the families in the present study were not experiencing any significant difference in "life stressors." Hypothesis 1 was, therefore, not supported. It could be inferred that the homeostatic functioning of the families has not been challenged by concurrent life strains at the time of study. This indicates that a pile-up of demands may not always occur in families experiencing chronic illness, although such demands or life events may arise at another time. Another possible explanation may be that since the events recorded covered only the past twelve months in the family's life, transitions and changes that may have taken place earlier were not reported. It would also appear that the families in the present sample do not carry with them a residue of prior strains.

The cumulative effect of life stressors in relation to the incidence of normal childhood illness, such as respiratory infections, has been demonstrated (Boyce et al. 1977).

Accordingly, life events and changes may increase vulnerability to illness or impede family compliance with a medical regimen.

Therefore, the experience of additional life stress and events for any family with chronic childhood illness may further consume the family's coping and resources, and would be likely to make their adaptation to illness more difficult (Berden 1990, MacLean et al. 1992).

6.4.2 Resources for Management

Referring to the resiliency model, a capability may be defined as the family's potential to meet the demands of the medical stressor. Three potential resources have been identified which may be relevant for the family's health: individual family members, the family unit, and the community.

Families of leukaemic and nephrotic children scored significantly higher than families of asthmatic children on the resource of "family strength I: esteem and communication," thus supporting hypothesis 3a. This resource is also maintained by families of nephrotic children in comparison to the control sample. The resource reflects the presence of a combination of personal, family system and social support in the following areas: family esteem, sharing of feelings (communication), decision-making, mutual assistance, encouragement of independence and autonomy, and problem-solving skills (McCubbin and Comeau 1991). The utilisation of the resource has the potential to assist families in managing and adapting to the stress of the childhood illness.

"Family strength I: esteem and communication" is also an indicator of high self-esteem, which is a facilitator of coping (Garmezy 1983). In relating this assumption to the experience of chronic childhood illness, families who have esteem would be more competent in managing the stress which is likely to filter through to all family members.

It has been suggested that "esteem" fosters a supportive family environment, characterised by high cohesion, expressiveness and low conflict (Moos 1976). Such parents would be better equipped to create an environment conducive to positive communication and expression (Satir 1972). "Communication" has consistently been found to be a good predictor for family coping (Spinetta et al. 1981, Kupst and Schulman 1988). Such parents are more sensitive to the cues of their children, and other family members (Walster and Walster 1978). They would also encourage responsible, independent and decision-making behaviour on the part of the ill child and other members. In this regard, ill children frequently feel insecure in situations over which they have little control. Being allowed to make decisions would contribute to a feeling of having some control. High esteemed parents are less controlling and concerned about their child's involvement in inappropriate activities; they are also less restrictive (Small 1988). The encouragement of independence, which is also reflected by the use of this resource, would naturally follow. In this context, research has consistently shown that the granting of acceptance and psychological autonomy are significantly related to a child's self-esteem (Crase et al. 1981, Kawash et al. 1985).

Hence, parents who possess high self-esteem are more likely to raise children who are competent and who have a strong sense of self-worth. However, a weak association was found to exist between family patterns of coping and resources and

children's self-esteem. This may be attributed to the instrument used in the present study which measures coping and resources, rather than the global self-esteem of the parent.

The families of leukaemic and nephrotic syndrome children are also "receptive to mutual assistance from others," a characteristic of family strength I. Such behaviour has been regarded as a "protective mechanism" (Garmezy 1985). There may be a beneficial reciprocal relationship whereby there is a sharing of physical and emotional responsibilities, especially with the caretaking of the ill child. This characteristic may be found in many Indian families since it is not unusual for a child to be reared by an extended family member. Hence, in the case of a chronically ill child, such assistance and support from family members may be welcome. Venters (1981) noted that access to ideas and information about child rearing, emotional and material assistance, and the social and cognitive stimulation of the child are some of the effects of such support. Thus, social support behaviour may play a key role in determining the extent to which the stressor associated with being a parent of a chronically ill child induces adverse psychological consequences (Kazak 1988, Speechley and Noh 1992). In this context, parents of leukaemic and nephrotic children tend to meet frequently on clinic days, thus forming a group which tends to be supportive of its members. This is probably not the case with families of asthmatic children, whose visits are sporadic.

The use of "family strength I" by families of leukaemic and nephrotic children reflects a "problem-solving ability" which is incorporated into the family system, and has been found to be particularly important when such families are confronted with stressful issues (Garmezy 1985). This ability may be

viewed as facilitating the adjustment of specific and non-specific stressors experienced by families in the two illness groups. Problem-solving strategies have also been proposed as effective skills used by stress-resistant children (Masten et al. 1988) and would be beneficial if taught to children experiencing chronic childhood illness.

Thus, families of leukaemic and nephrotic children demonstrate characteristics which are conducive to the positive adaptation to chronic childhood illness (McCubbin 1991), particularly in comparison with families of asthmatic children. These families not only appear to have maintained their identity and esteem in the face of an unpredictable illness, but demonstrate psychological stability in managing the pressures and trauma of caring for a chronically ill child.

The families of leukaemic and nephrotic children similarly scored significantly higher than the families of the asthmatic and control children on the "financial well-being" resource, demonstrating perceived financial efficacy. This finding was substantiated by the significantly higher income among families of leukaemic children than among families of asthmatics and control children. Many areas of family functioning are dependent on financial resources - for example, family social activities, transportation and medical costs - which may easily be disrupted if the resources are meagre (Wallender et al. 1989). While these families display resources with which to meet the health care costs (and display possibly one less stressor than the families of asthmatics), they also demonstrate a positive perception of their ability to meet their commitments in respect of their ill child and other family members. Having adequate monetary reserves may mean that the family would be more secure in planning the future of their children. This capacity to plan

for the future may also be the reason why families of nephrotic children scored higher on the "limits of family opportunity" scale, expressing greater concern about their children's educational and career prospects.

Not surprisingly, these findings are inconsistent with those of Vance et al. (1979) which point to the financial burden faced by families of nephrotic children in the United States, where health care costs are excessively high. The present sample was obtained from a state hospital, where financial costs for the family are substantially lower than for families attending a private hospital.

This scale also reflects the availability of resources to help others in need. This appears to be characteristic of families of leukaemic and nephrotic children who may be more able to assist others in need, thereby extending their social network services. The families of leukaemic and nephrotic children also reflect an optimism about their financial future, a perception which may facilitate planning for the future.

The appropriate management of the "financial well-being" resource may have implications for the reduction of stress in families experiencing chronic childhood illness. For instance, it was found that the more the "financial well-being" resource was used the less the stress experienced in the areas of "poor mood/health," "excess time demands," "overcommitment/martyrdom," "overprotection/dependency," "limits on family opportunity," "lack of activities for index case," and "difficult personality characteristics" (cf. 6.7.1).

The "financial well-being" resource was also marginally associated with the frequency of children's coping strategies. Children who use the "self-criticism" and "wishful-thinking" coping strategies were mainly from families who did not have financial resources. Such children are more likely to be critical of themselves and to fantasise if their families experience problems financially. While the availability of this resource may be fortuitous for families of leukaemic and nephrotic children, it would undoubtedly aid in relieving some of the stresses experienced as well as improving their life-style and managing the medical expenses. Hence, financial and family psychological resources appear to be important variables for child outcome, being related to coping and adaptation in the ill child (Steinhausen et al. 1983, Wallender et al. 1989).

As hypothesised, families of chronically ill children scored significantly differently in respect of their management of resources. In particular, the finding that families of leukaemic and nephrotic subjects scored significantly higher than the families of asthmatic subjects on the "resources for management" scale suggests that the first two groups of families have more resources available than families of asthmatic children. This validates the findings obtained above.

A number of explanations are possible for the poorer management of resources by the present sample of families of asthmatics. Firstly, families of asthmatic children have a relatively lower income than families in the other two illness groups. They may be more susceptible to both physical and financial hardships, as well as the associated psychological stress. The stressors expressed by the families of asthmatic children may be aggravated by the additional costs incurred from living with many family

members. The lower socio-economic status and lower educational qualification of this group suggest that they are more likely to work longer hours in skilled and semi-skilled positions. This would reduce the family members' energy levels and time devoted to different members (Voydanoff 1988) who may also be emotionally demanding. The lack of financial resources may also mean that they do not have a choice of treatment facilities, and may be forced to seek care at a state hospital, unlike the other illness groups.

The experience of high levels of stress by the mothers, as indicated earlier, would mean that the asthmatic group may require more information, assistance with resource management and social support than is accorded to the average patient. Psychosocial intervention is strongly recommended for the families of asthmatics.

6.4.3 Health-Related Coping Patterns

In the resiliency model, coping is a specific behaviour by which an individual or group attempts to reduce or manage the demands of chronic illness on the family system. Coping behaviours, therefore, may vary with the adaptation of the mother and the family system (Caplan 1981).

The findings of this study add to the efforts to identify the competencies of families of children with asthma, leukaemia and nephrotic syndrome. As hypothesised, there were significant differences among the parents of asthmatic, leukaemic, nephrotic and control children in their health-related coping patterns.

The leukaemic and nephrotic subjects scored significantly higher than the asthmatic subjects on "coping pattern I." This would seem to suggest that parents of leukaemic and nephrotic children employ behaviours to encourage family integration, co-operation and an optimistic definition of the stress situation of chronic illness. Such coping efforts demonstrate the ability to focus on strengthening family relationships, as well as enhancing their outlook on life with their chronically ill child, and maintaining the family morale (McCubbin 1991). These findings are consistent with those of McCubbin et al. (1983).

"Coping pattern I" has been found to be associated with less stress in the area of "lack of family integration," "financial problems" and the "difficult personality characteristics" of the ill child. One may infer that parents of leukaemic and nephrotic children experience less stress in these areas and more family harmony than is experienced by parents of asthmatics because they utilise an effective coping behaviour.

This coping pattern also has positive consequences for the choice of coping strategies selected by the child. The "self-criticism" coping strategy was not used as frequently by children whose parents who used "coping pattern I." Coping pattern I, therefore, appears to be a positive behaviour in the adaptation of families to chronic childhood illness.

"Coping pattern III" was utilised by parents of leukaemic and nephrotic subjects more than parents of the other two groups. "Coping pattern III" comprises behaviour patterns which encourage communication with other parents and consultation with health professionals. These behaviours are directed at

acquiring medical knowledge, fostering relationships with parents of children with similar illnesses and endeavours to follow the prescribed treatment regimens diligently. Such behaviours would facilitate an understanding of the illnesses of the children. These results point to a different process for negotiating stress among the two groups in comparison with the families of asthmatics. As indicated earlier, the information gained about the medical condition predicts coping and adaptation for families of children with chronic childhood illness. When parents receive limited information from health professionals, they worry about what the child will be like in the future. In this regard, Baxter (1986) reported that parents indicated that the most important type of help they had received from professionals was information, and that help was more important to them than emotional support. This coping behaviour has important implications for availability and openness by members of the health care team.

Support in the form of close relationships with parents of other chronically ill children may serve a special purpose for parents in learning to cope with the child's illness. Contact with other parents in similar situations may also act as a self-help or cathartic strategy. This coping pattern is, therefore, an attempt to reduce or alleviate the stressful impact of the condition, and reflects appropriate coping behaviour (McCubbin 1991). These findings substantiate the need for regular support groups among parents of chronically ill children.

The present finding also suggests better compliance with health care treatment regimens among these families. Such health-related behaviour, involving family structure, may need to be maintained as families of ill children would be required to facilitate on-going medical regimens and care.

It may also encourage appropriate problem-solving behaviour, particularly when the family is confronted with a painful crisis associated with the illness. In this context, family coping has been viewed as the co-ordinate problem-solving behaviour of the whole family system (Klein and Hill 1979), and may involve the complementary efforts of individual members (McCubbin and McCubbin 1991).

The day to day stresses may necessitate more closeness and co-operation among all family members if the household is to function effectively; for instance, the child may be required to take medication, maintain a diet, or visit the hospital regularly. These practices usually demand a discipline not required of non chronically ill children. It may be necessary for parents and family members to guide and reinforce certain procedures which may have to become routine. In an effort to reinforce these essential health maintenance practices for the ill child, parents may increase the discipline and role definition of all members in the family. Hence, these findings emphasise the need for programmes designed to promote routine and structure within the family.

The more effective coping patterns displayed by families of leukaemic and nephrotic children may be related to the higher educational level in comparison with the families of asthmatic children. For instance, the present study found that a higher educational level of the mother was related to the coping patterns used. Only these two groups (leukaemic and nephrotic) had parents who had university degrees (8,7% and 4,55% respectively) and an even larger percentage had post-matric qualifications (34,78% and 18,18%, respectively) compared to the families of asthmatic children with none having university education and only 13,33% with post-matric education.

"Coping pattern III," used by individuals in the nephrotic and leukaemic groups may also be reinforced by the care of the doctors and other health professionals treating the children. Hence, managing the member with a long-term chronic condition requires a complementary relationship between the heath care team and the family unit. How the parents cope with the situation could make a difference to the health status of chronically ill children (McCubbin et al. 1983).

Thus, parents of children with leukaemia and nephrotic syndrome respond to the realities of their children's illness with appropriate health-specific coping strategies. These coping behaviours assist in alleviating or adapting to the stress of chronic childhood illness (McCubbin 1991). Similar findings were reported by McCauslin (1984) and Donovan (1985) for mothers of handicapped children.

The finding that there were no significant differences in the health-related coping patterns of parents of asthmatic and control children suggests that parents of asthmatic children function very much in the same way as parents of healthy children. One explanation may be that the condition is not as visible as in leukaemia and nephrotic syndrome, and therefore has not required a major change in family functioning. On the other hand, the findings may reflect the lack of coping skills necessary for their adaptation to the chronic illness of asthma. Given the special needs of asthmatic children, these families may not have sufficient information, services or resources to mobilise their skills. For example, events such as compliance with medical routines may become stressful and disruptive to families of asthmatic children, especially if not managed appropriately. Thus, in the case of families of asthmatics, the expected coping behaviour may not occur, may be mediated by another strategy

not identified in this research, or may be ineffective. This is supported by the findings of the present study (cf. 6.7.2) where an association was found between the use of fewer coping skills and higher levels of stress. In particular, the less coping pattern I was used, the greater the stress of "lack family integration" (an area of stress reported by families of asthmatic children).

It may also be true that families of asthmatics who have difficulty adapting to the illness are those that had more problematic levels of adjustment before the illness (Kazak 1989). Their coping behaviours, which are usually developed over time, may no longer be effective.

Thus, it seems that the illness group of asthma not only experiences crises and excessive demands, but has depleted competencies and resources. These are factors which are associated with the deterioration of the level of functioning in a family (Lewis and Looney 1984). The families' resiliency may be compromised. Psychological intervention would be required to change the existing structure and restore functional stability as well as improve family satisfaction. This may entail the modification of established roles, rules, goals and patterns of interaction in these families. The re-education of coping strategies (which provide families with ways to behave and to make responsible choices) should also be taught. Moreover, once these changes have been made, members may need to consolidate the family unit into a coherent and cohesive unit in support of the changes. This process would naturally evolve as families work towards adaptation.

The lower educational level of parents of asthmatic children may also mean that these families do not have an effective

repertoire of coping skills. As this group is also at high risk for personal and family stress, psychological support is strongly recommended. Finally, it is imperative that medical education, information and intervention programmes be designed to suit the educational level of any illness group if it is to become effective.

6.4.4 Family Crisis-Oriented Coping Strategies

Internal and external family interaction behaviours and coping strategies may also be used by families in their experience of chronic childhood illness.

As hypothesised, there were significant differences in family-oriented coping strategies between the illness and control groups. In particular, families of nephrotic children scored significantly higher than the families of asthmatic and control children on the "seeking spiritual support" coping strategy. This strategy reflects the family's involvement, faith and reliance on religious and spiritual activities and ideology in times of stress. Such religious and spiritual involvement may facilitate a different appraisal of, and possibly reduce their perception of, the chronic stress. The stress-buffering properties of religious involvement and support have been affirmed (Peterson and Roy 1985, Krause and Van Tran 1989). Barden (1991) has stated that a positive attitude is most noticeable in families experiencing chronic illness, since they have a consistent philosophical, religious or cultural perspective that incorporates life's difficulties into a coherent framework of productive beliefs. Thus, it may be inferred that this groups' involvement with spirituality supports them in their adaptation to the stress of chronic childhood illness.

The finding that families of nephrotic children were not significantly different from families of leukaemic children on this measure, but significantly different from families of asthmatic children and the control group, suggests that the leukaemic group is also spiritual in their outlook. Hence, these two groups of families would appear to "seek solutions through an enlargement of their existing philosophies to provide a personally meaningful definition to their situation" (Venters 1981). It seems that families of asthmatics (like the control) do not feel the need for spirituality that the other illness groups display, despite having "sought assistance from a priest," as did the other illness groups.

The nephrotic group also scored higher than the control group on the "mobilising family to acquire and accept help" coping strategy. The "mobilising" coping behaviour focuses on obtaining support by communicating, engaging in activities, and receiving help and support from professionals, community programmes, and others.

This coping behaviour underscores the importance of the "active effort" to engage help, seek counselling services, and consult with health professionals. Thus, families of nephrotic children utilise strategies that call upon external assistance to facilitate family adaptation. Families of nephrotic children, therefore, recognise the value of therapeutic help outside the family. In this context, the present study also found that the less the "acquiring social support" strategy was used, the more the "lack of family integration," signifying once again the therapeutic value of prosocial support behaviour.

The findings discussed above have important implications for health care research and family systems medicine. The coping behaviours described play a role in understanding why some families are unable to cope in the face of chronic illness. The findings also contribute to an understanding of the role of the family system in designing medical, community and outreach programmes and interventions, in order to promote recovery and care of patients receiving continuous therapy.

Hence, families of children with nephrotic syndrome, in comparison with the other illness groups, appear to handle the difficulties experienced amongst their members by being spiritual, which is an internal resource. They also employ active behaviours to acquire the resources outside the boundaries of their family unit (McCubbin and Patterson 1991). These characteristics reaffirm that internal and external coping behaviours may reduce or mediate a stressor, thereby enhancing the successful adaptation of families to chronic childhood illness. Such competencies would reduce the stress on parents, encourage the continuing emotional growth of the child and family members, and allow for the development of individual responsibility.

The finding that there was no significant difference between the leukaemic and control groups, and the asthmatic and control groups in family coping strategies suggests that these groups of families respond with similar crisis-oriented coping strategies. However, in view of the demands of both illnesses, it may be possible that the two illness groups are unable to handle problems that emerge outside its boundaries but affect the family unit. Empirical research into intervention with these groups is suggested, in order to assess effectiveness.

These results allow for the identification of families who will be vulnerable to psychosocial dysfunction due to ineffective coping patterns and poor management of resources, as well as those who are more resilient. This information may be incorporated into an intervention programme which promotes the teaching of effective coping strategies and the management of resources, as well as providing the therapeutic context for implementation. Also, at a preventive level, it is suggested that psychosocial skill programmes be developed to encourage competence and esteem in the family unit.

6.4.5 Conclusion

The above findings suggest that a model of family stress and coping provides a useful way to conceptualise and organise relationships among the array of variables that potentially influence the adaptation or outcome of illness (Barbarin 1983, McCubbin and Thompson 1991). Such a model underscores the importance of empirically identifying individual competencies or resiliency in the child and protective characteristics or family coping skills and resources which buffer the effects of the chronic stressor.

The results of the present study indicate that the resources available to the family and the competencies of its members should be considered for their contribution to the task of coping with the stressors of chronic childhood illness. With the current changes in the delivery patterns and reimbursement structure for health care, families will be called upon to increase their responsibility for maintaining and supervising the care of chronically ill members. These findings offer a description of the characteristics of coping and resources which are working for some families and may be applicable to others. It is likely that these factors assist

in distinguishing those families who successfully weather the crises and changes associated with their child's illness from those who are less adaptive.

However, a limited repertoire of resources and coping skills has been used by all three groups in this study. This would imply a lower degree of adaptation by the family system (Caplan 1981, Thoits 1986). The larger the repertoire of resources and coping skills, the easier the adaptation of the family to the stress of the illness (Wallender et al. 1989, McCubbin and McCubbin 1991). It is possible that the present sample, by their exposure to socio-political and other environmental stresses (including the poor quality of health care which is frequently present in developing countries) have not been able to exploit the vast pool of psychological behaviours or resources necessary for more efficient adjustment. The present findings may also reflect culture-specific trends in the responses of these families to the stresses of chronic childhood illness.

The impact of chronic childhood illness may be viewed as a process that may interact with the unique characteristics of the child and his/her family. "Ultimately the family acts as a recipient of the stresses associated with the child's illness and has the greatest impact on the psychological adaptation and outcome of the child" (Hamlett et al. 1992 p 46).

6.5 Phase of Illness and Stress, Resources, Coping and Adaptation

How families adjust and re-adjust to the demands of different phases of the illness will determine how well the child and

his family members have learnt to integrate the illness into their daily lives (Drotar et al. 1984). The present study examined the adaptation of families in the phases of induction and remission. As there is a relative lack of research investigating the variables under study in children with nephrotic syndrome, reference and comparison in respect of the phase of illness have been made with research on children who have cancer.

Children and their mothers were younger in the induction phase than those in remission. This substantiates earlier reports that illnesses such as leukaemia and nephrotic syndrome occur early in childhood (Sather 1986, Silverberg and Lubera 1987, Coovadia and Loening 1992).

As hypothesised, there were significant differences in stress between the remission and induction sub-groups. This finding suggests that the phase of illness may be associated with the stress experienced by the families. This is consistent with certain theoretical viewpoints (Eiser 1990, Friedman and Mulhern 1992).

Mothers with children in the induction phase experienced more stress than those with children in remission, on the "excess time demands" scale. This may be due to the younger age of the children in this phase of illness, who would naturally be more dependent on the parent. Having a child in induction (as compared to remission) would elicit greater responsibility on the part of the mother, with more demands on her time. As previously indicated, the treatment administered to the child in the induction phase is associated with many negative side-effects, such as loss of hair, nausea, vomiting, ulcers, diarrhoea and headaches. These children are also sometimes isolated at home to prevent

infection. Thus, Kalnins et al. (1980) report that parents and children undergoing chemotherapy experience a variety of stresses, which may continue regardless on the outcome.

The "physical incapacitation" scale was also scored higher by mothers who have children in the induction phase than those who have children in remission. It is likely that children in the induction phase may experience more problems pertaining to their health, and also have difficulty with self-help functioning and ambulation. They may also have difficulty participating in sporting and other outdoor activities. As leukaemia and nephrotic syndrome are serious illnesses, often necessitating intensive treatment in the induction phase, the perception of poorer physical capabilities by the mothers may reflect the physical condition of the children. It is also necessary to note that leukaemia is the only one of these diseases where the induction phase is associated with particularly unpleasant experiences, which in itself is bound to cause distress.

The findings suggest that families who have children in remission experience less stress, and may adapt. This would seem to suggest that the fear of a relapse may not always be present. Kupst and Schulman (1988) have found that families of leukaemic children display stable coping six years after diagnosis. Thus, families with children in remission tend to approximate families with healthy children. Other studies have also indicated that childhood cancer survivors (in varying age groups) score near normative levels in terms of psychological and social functioning (Wasserman et al. 1987, Greenberg et al. 1989).

There were no significant differences between the families with children in remission and those in the induction phase

on the management of resources, health-related coping patterns and crisis-oriented coping behaviour. Thus, irrespective of the phase of illness, both groups of families appear to be similar in respect of certain competencies, that is the management of resources and coping abilities. This may possibly be attributed to the strengths, and overall functioning of both groups of families, and to the supportive care of doctors. While direct comparisons with other studies were not always possible, researchers have referred to family communication as being a predictor of long-term coping with cancer (Kupst and Schulman 1988, Kazak and Meadows 1989). Coping does not mean a linear progression of growth without setbacks (Spinetta et al. 1981). However, it has been found that long-term coping with paediatric leukaemia is associated with the level of family support, quality of parental relationship, the coping abilities of other family members, lack of concurrent stresses and open communication within the family (Kupst and Shulman 1988).

Since this study was not longitudinal in design, adaptation over time could not be measured. However, it was found that while families who have children in the induction phase experience greater stress than those in remission, they do not utilise different resources and coping behaviours (from the first group) to assist them in the treatment phase of the illness. Intervention is recommended to incorporate the teaching of coping strategies and the resources that may be drawn upon to reduce the stress experienced by families of chronically ill children in the induction phase.

6.6 Gender and Stress, Resources, Coping and Adaptation

As hypothesised, there were significant gender differences in the stress profiles of families. Mothers of boys scored significantly higher than mothers of girls on "poor mood/ health," "excess time demands," "overprotection/dependency," "limits on family opportunity" and "physical incapacitation."

The finding that mothers of boys experienced poorer mood and health, with greater demands on their time, suggests that boys are a source of greater physical and emotional stress for their mothers. They may also be perceived as more demanding. This may reflect the anxiety and difficulty of mothers in managing boys. MacLean et al. (1992) also found that the behaviour of boys appears to be more conspicuous to parents; this is viewed as an unhealthy adaptation by them.

Mothers perceived boys as being dependent on them for physical assistance and were more protective towards them. This attitude possibly highlights a cultural bias in respect of the gender of the child as some Indian mothers encourage a sick role or dependency behaviour in their sons. In contrast, Whiting and Edwards (1988) have suggested that traditionally parents are more sympathetic and nurturing to girls. Eiser et al. (1992) have also found that mothers differentiated between chronically ill children in terms of gender. However, the girls were perceived as having more problems in relation to dependency. Mothers more than fathers were found to encourage illness behaviour in their sick children (Walker and Zeman 1992).

The present study revealed that families with boys believed that they had to forego opportunities for employment, education and social and personal growth. This response may be characteristic of Indian families who have traditionally "sacrificed" much in respect of their sons' advancement (Mahabeer 1989).

The finding that there were no significant differences between the families of boys and girls in respect of resources and health coping patterns possibly reflects that the gender of the child has no influence on the management of resources or health-related coping behaviour. However, in view of the stress experienced by families in relation to boys, particular consideration needs to be given to the teaching of appropriate coping skills and resources to families and mothers of boys.

It was also found that families respond significantly more to the "passive appraisal" coping strategy in respect of girls. This reflects the family's ability to accept problematic issues, reducing the tendency to react overtly and avoid difficulties and stresses, and a reliance on luck and time to resolve problems. A number of factors may elicit this type of coping strategy on the part of parents. Girls may not appear to contribute as much stress to the family as boys do. They appear less demanding, do not display as many behaviour problems (MacLean et al. 1992), are possibly more independent, and therefore not as over-protected, than boys tend to be. Parents appear to respond to their daughters with a cognitive appraisal coping strategy than an active coping mechanism.

Families were found to respond to the "mobilising family to acquire and accept help" coping strategy in respect of girls.

This coping strategy reflects the family's efforts to seek out community resources and accept help from others. Thus, positive social and helping behaviour may be shown and encouraged by girls.

6.7 Specific Stressors associated with Resources and Coping Patterns

As hypothesised, certain stressors correlated negatively with certain resources and specific coping patterns. This suggests that the utilisation of these resources and coping skills are associated with the different stressors related to chronic illness.

6.7.1 Resources

Certain resources were found to be significantly associated with areas of stress.

The "family strength I: esteem and communication" resource correlated negatively with the stressors of "excess time demands," "lack of family integration," "limits on family opportunity," "financial problems," and "difficult personality characteristics." This suggests that the characteristics of esteem, communication, problem solving ability, optimism, mutual assistance and encouragement among family members are related to the integration of its members, to the perception of fewer financial problems, to more opportunities for family members, and to better perceptions of the child.

The utilisation of "family strength II: mastery and health" - that is, a sense of mastery over family events and outcome, family mutuality, physical and emotional health - were associated with the reduction in the stress of "poor mood/health," "excess time demands," "negative attitude toward index case," "overcommitment/martyrdom," and "financial problems." The use of the resource of "family strength II" seem to contribute to a lessening of the stressors.

The non-utilisation of the "extended family social support" resource correlated negatively with the stressor of "occupational limitations." This suggests that non-participation by families in respect of assistance and support may add to the stress of experiencing limited education and work opportunities.

Families who do not have the "financial well-being" resource are associated with the stressors of "poor mood/health," "excess time demands," "overprotection/dependency," "overcommitment/martyrdom," "limits on family opportunity," "lack of activities for index case," and "difficult personality characteristics." This suggests that the resource reflecting the family's ability to meet their financial commitments, having an adequacy of financial reserves, the ability to help others and optimism about the financial future are associated with less stress in the areas documented. Similarly, it was found that families who do not use the "sources of financial support" resource are associated with stress in the area of time demands, limitations on opportunity, and financial problems, pointing to the beneficial aspects of financial support for families.

The "social desirability" resource was associated with the stressors of "limits on family opportunity" and "financial problems," suggesting that opportunities for family members and the estimation of their financial situation are influenced by societal norms. This suggests that the perceptions certain families have of their educational, occupational and financial status are strongly influenced by significant others in the community, and society.

6.7.2 Coping Patterns

Significant associations were found to exist between certain coping patterns and areas of stress. In particular, "coping patterns I and II" were associated with the stressors of "lack of family integration," "financial problems" and "difficult personality characteristics." This suggests that coping pattern I, which reflects the attempt to maintain family integration, cooperation and an optimistic definition of the situation, and II, which is aimed at maintaining social support, self-esteem and psychological stability, would contribute to family cohesiveness, less financial stress and a diminished perception of the child as being difficult.

Interestingly, a relationship was found between "coping pattern III" and the stressor of "financial problems." It is likely that behaviours directed at understanding the condition through communication with other parents and with health professionals would foster an understanding of the illness, thereby preventing a possible interruption of employment on the part of significant family members with fewer financial problems resulting.

Families who do not respond to the coping strategy of "acquiring social support" are associated with "lack of family integration." Thus, the lack of efforts to obtain outside help and social support appears related to stress among family members and difficulty in family functioning. This pattern of interaction may be a symptom of one or more difficult personalities in the family.

These findings identify significant relationships between specific resources and coping patterns used by families, and stressors experienced within a family system. This suggests that the use of particular resources and the identified health- related and family-oriented coping patterns, may contribute positively to the experience of chronic illness. These patterns of behaviour may have therapeutic benefits if taught to parents and families who have children with chronic illness.

6.8 Children's Coping Strategies

Chronic illness is a major stressor in a child's life. Since patterns of coping behaviours or skills are important in mediating the adverse effects of the illness and assisting the child in his psychological adaptation to the illness, an examination of these variables was considered important.

It was also necessary to explore the value of coping strategies in relation to specific diseases experienced by children - in other words, the extent to which the coping skills of children were determined by the characteristics of their illness. This examination involved a comparison across the illness groups of asthma, leukaemia and nephrotic syndrome, and the control group. As hypothesised, there were

significant differences in the coping strategies of children across the illness groups and the control group.

6.8.1 Coping Strategies of Asthmatic and Control Children

The finding that there were no significant differences between the asthmatic and control children in the use of coping strategies indicates that asthmatic children cope in a manner similar to control children. While this may indicate that an asthmatic child is not impeded in the use of coping mechanisms because of his illness, the absence of any differences in coping strategies may also reflect the lack of effective use of coping strategies on the part of asthmatic children, particularly in view of the stress experienced with their illness. This may negatively affect their adaptation to the illness. For example, stressors such as the suddenness of attacks, which may be life-threatening and which require continual readjustment, may require the use of different strategies more frequently than is used by a healthy child. It is also likely that children suffering from asthma have not had the time to learn effective coping skills because of the intermittent nature of their condition.

Previous research has acknowledged that the child's adjustment is affected by the levels of stress and symptoms experienced by other family members (Daniels et al. 1987, Compas et al. 1989). The adjustment of a child to his normal developmental tasks, as well as to the challenges of his illness is also related to family styles of coping and adaptation. The finding of relationships between certain coping skills in children and resources and coping patterns used by families may contribute to the overall coping ability of the child (cf. 6.7.2). Here, reference is made to earlier

discussions concerning stressful family circumstances, and the coping patterns and resources used by mothers of asthmatic children and their relationship to the children's choice of coping. Mothers of asthmatic children were found to experience distress and discontent relative to the child's illness. Families of asthmatic children were also found to experience a significant lack of family harmony, intra-familial problems and poor economic conditions (not necessarily due to asthma). Asthmatic children were also perceived as physically incapacitated and were, consequently, over-protected by and dependent on their mothers. Thus, the family environment of asthmatic children in this sample may not be conducive to the development of effective coping skills by the child.

6.8.2 Coping Strategies of Leukaemic and Control Children

The leukaemic group scored significantly higher than the control group on the "social withdrawal" coping strategy. The use of this coping strategy may be specific to the stressor of the illness. For instance, even young children would realise that their illness is no ordinary illness and would feel different from other children, thereby withdrawing from others. Physical changes such as loss of hair and weight gain (due to medication with steroids) may also increase their feelings of being different and of being a curiosity other children, as well as increasing the opportunity of peer teasing. Withdrawing socially may be one way of avoiding the resultant stress or anxiety.

"Social withdrawal" may also be the reason why leukaemic children were found to have significantly fewer peer relationships. These findings are consistent with that of

Kager and Holden (1992) who found that children's coping skills were directly related to peer relations. Children who reported the use of particular coping strategies more frequently also felt more secure in their relationships with peers.

The leukaemic children used "distraction" marginally less than the control group of non chronically ill children. This finding is surprising, as children with leukaemia have had many opportunities to learn and practise internal types of coping in response to their frequently uncontrollable illness-related stressors. Spirito et al. (1988) found that distraction was employed by paediatric patients who were referred for psychological evaluation. Thus, "distraction" is a characteristic response of a child to stress but may be more available to children who have the capacity to use fantasy. The use of a particular coping strategy may vary with different children and across situations (Folkman et al. 1985, Redd et al. 1987, Bull and Drotar 1991).

6.8.3 Coping Strategies of Nephrotic Syndrome and Control Children

The nephrotic group scored significantly lower than the control group on the "distraction" coping strategy. This finding may reflect once again that children with nephrotic syndrome (like leukaemic children) tend not to use the coping strategy as frequently as non chronically ill children do. Comparison with research in the area of nephrotic children's coping has not been possible because of the lack of available data. However, distraction, as indicated above, may be effective in many stressful situations.

While attempts at coping through disengagement may be maladaptive in certain individuals or in certain circumstances, it may be effective with health-related stressors. "Distraction" or "disengagement," interalia, have been found to be effective in coping with various aspects of a chronic illness (Spirito et al. 1988), and may be important in successful adaptation to chronic illness (Miller and Green 1984). Therefore, the enhancement of effective use of this strategy would have enormous benefits for children with nephrotic syndrome (and with asthmatic and leukaemic children as well). In this way, children would be better equipped to handle the frequent untoward episodes which have to be anticipated over the course of their illness.

6.9 Coping Strategies of Chronically Ill and Control Children

As hypothesised, there were significant differences in the use of coping strategies between children with chronic illness (N = 75) and those of the healthy control group (N = 30). The chronically ill group used "distraction" significantly less and "social withdrawal" significantly more than the control group. This behavioural pattern has probably developed in response to the stressors of the illness. It is possible that the ill children have abandoned attempts at learning skills to master the situation, and have acquiesced to the on-going medically-related stressors. Another explanation would be that since coping behaviour is a learned response to aversive stimuli, such patterns represent the acquired responses of children to the stress of illness.

The present study found that children with chronic illness do not use many coping strategies. This is contrary to the nature of the stress which requires that children with

chronic illness be adept at generating a variety of coping strategies in dealing with the stressful illness experience (Lazarus and Folkman 1984), and that a limited repertoire of strategies may be associated with a higher incidence of behavioural and emotional problems (Robins 1987). Hence, it is recommended that should incorporate the teaching of various coping strategies to children confronted with any illness stressor. The benefits of flexibility and change in the use of strategies should also be emphasised.

It also seems likely that the illness stressors have important implications in respect of the ill child's coping skills, which not only influence the course of the illness but also the child's overall adaptation to it. According to Barden (1991 p 369), successful coping experiences in childhood enhance the general flexibility and resiliency of the child, thereby increasing the likelihood of adaptive stress management in the future. Conversely, repeated failures in coping with stress are thought to result in frustration, anxiety, and the possible development of a defensive rigidity, predisposing the child to later adaptive difficulties. It has also been suggested that, as children pass through adolescence, they may continue to engage in the negative and ineffective coping strategies they had learned previously (Gill et al. 1991) - in this case, greater social withdrawal and not coping by distraction. The lack of effective coping skills may become entrenched as children grow older. Therefore, intervention programmes designed to teach and enhance coping skills in children with chronic illness should be implemented early. By implication, intervention should help chronically ill children appraise the potential stress of the situation, and assist in the selection of different strategies. The child may also be taught to selectively attend to a less threatening aspect of the stressor or event, or cognitively transform how the event is processed, and may even be distracted from the event.

The finding of the use of "distraction" as a coping strategy by children in the control group may reflect a cultural bias, where Indian children are discouraged from acting out, and therefore tend to cope more passively. This strategy may also serve as a protective factor which possibly contributes to resiliency on the part of a somewhat disadvantaged group of restrained children.

The present findings are also inconsistent with the literature, which indicates that physically healthy children use a variety of coping strategies more consistently than adults in response to a range of academic, family, social and health-related stressors (Folkman and Lazarus 1980, Wills 1986, Compas et al. 1988). While this may reflect a limited repertoire of coping skills on the part of the children studied, it may also be that the instrument, which was designed for an American sample, does not adequately assess all the skills used by the present cultural group.

6.10 Phase of Illness and Children's Coping Strategies

The finding that there were no significant differences between children in the remission and induction phases in the use of coping strategies indicates that the coping approaches of the two groups do not differ significantly. It is possible that the two groups of children (that is, those suffering from leukaemic and nephrotic syndrome) cope similarly, irrespective of the phase of illness. However, although children in the induction phase experience increased medical stressors, they surprisingly do not utilise coping strategies effectively. Intervention is recommended to incorporate the teaching of coping strategies to reduce stress and facilitate a positive adaptation to the illness.

6.11 Gender and Children's Coping Strategies

There were no significant differences between boys and girls in the use of coping strategies, indicating that the gender of the child has no association with the coping strategies used. This is consistent with studies which indicate that young boys and girls do not use different strategies (Brown et al. 1986).

Some studies have identified a trend towards more females than males utilising relationship skills and emotion management for general life stress (Czajkowski and Koocher 1987, Compass et al. 1988, Bull and Drotar 1991). However, gender differences in the use of different strategies of coping are more likely to occur as children grow older, and be more noticeable in adolescence (Band and Weisz 1988).

In this context, research has shown that young children tend to use primary coping, since they prefer to perform some action to change the environment, rather use cognitive abstraction (Band and Weisz 1988). Younger children with cancer also report more often that "nothing works," while older physically-healthy children have been found to use more cognitive emotion focused coping strategies (Compas et al. 1988), as well as intrapsychic coping (Wertlieb et al. 1987), information-seeking coping (Peterson and Toler 1986) and secondary coping which requires more abstract thinking (Band and Weisz 1988). As children mature cognitively, they tend to use abstract thinking processes more. This is likely to influence the frequency of use as well as the choice of coping strategy, which also increases with maturity (Brown et al. 1986).

It is interesting that while families in the present study experienced more stress in relation to boys, and chose their family coping responses according to the gender of the child, children's coping skills were not associated with this variable.

6.12 The Relationships between

i) **Children's Coping Strategies and Family Resources,**

ii) **Children's Coping Strategies and Family Health-Related Coping Patterns, and**

iii) **Children's Coping Strategies and Family Crisis-Oriented Coping Strategies**

As hypothesised, certain coping strategies used by children were found to be significantly associated with the resources and coping patterns utilised by the families.

The non-usage of the "wishful thinking" coping strategy by children was significantly associated with the "sources of financial support" resources, suggesting that financial support may mean a realisation of attainment rather than fantasy for a desired object by the child.

The use of the "resignation" coping strategy by children was significantly associated with families who use the "extended family social support" resource. Hence, children who tend to give up trying are frequently associated with families who rely on the help of significant others.

Interestingly, close involvement with families who use the "extended family social support" and "acquiring social support" strategies also meant that children tended not to use the "problem-solving" coping approach, and possibly relied on others for assistance rather than rectify the problem themselves.

The non-usage of the "self-criticism" coping strategy by children was significantly associated with "coping pattern I." This suggests that the health-related style of coping by the parent, in particular efforts at maintaining family integration, cooperation and optimism about the situation, was associated with a non-critical attitude on the part of children.

The non-utilisation of the "blaming others" coping strategy by children was significantly associated with families who use the "reframing" coping strategy. Thus, children are more likely not to blame others when their families faced the demands and redefined the situation into a positive perspective.

The non-usage of the "blaming others" coping strategy by children was also associated with the "extended family social support" resource and "mobilising families to acquire and accept help" crisis-oriented coping strategy. This implies that children do not show a tendency to blame others for their predicament when their families are actively involved in the giving and receiving of support and assistance from relatives, the community, and professionals.

The family resources, health-related coping patterns, and family crisis-oriented coping strategies and resources

delineated above have important implications for the choice of coping strategy used by the child. The data point to a focus of interaction of behaviour patterns between parents and their children and emphasise certain effective qualities of competence in families as being necessary for the success of the use of specific coping strategies by children. These findings reaffirm the view that the teaching of appropriate coping strategies should be directed at the family since there is an association between certain coping skills used by children and the family patterns of coping and resources. The premise put forward by Drotar et al. (1984 p 103) may, therefore, be true: "Since chronically ill children learn strategies of coping and adaptation ... from transactions with family members, the quality of intra-familial coping is a critical component of the child's ability to negotiate the stressful demands .... " It follows that the manner in which parents deal with and resolve their own problems in relation to the illness may be associated with the child's coping ability. Thus, therapeutic intervention should focus on the development of effective coping patterns and resources in the families of children with chronic illness.

6.13 A Comparison of the Self-Esteem of Children with Asthma, Leukaemia, Nephrotic Syndrome and the Control Group

Self-esteem has been suggested as an indicator of the effectiveness of coping and adaptation by children. The relationship between overall adaptation and positive self-esteem has been discussed in earlier chapters. Successful adaptation of a child may be identified by the child's self-recognition of areas of competency and the presence of self-worth.

As hypothesised, there were significant differences in self-esteem among the four groups. The control group scored significantly higher than children with asthma and leukaemia on scholastic competence. A possible reason for this difference is that the conditions of asthma and leukaemia frequently result in sudden attacks (as is the case with asthma) and unpredictable deterioration of health, causing disturbances in concentration and difficulty in maintaining a reasonable standard at school. While this finding may reflect the anxiety and perception of the child regarding his scholastic abilities, it may also reflect lower competence as a result of decrements in stamina and motivation (Barbarin 1990). These results are congruous with previous research findings that some asthmatic and leukaemic children experience academic failures (Eiser 1980, Talyor et al. 1987, Hambley et al. 1989). The lower educational level of mothers in the asthmatic group (in comparison to mothers in the leukaemic and nephrotic groups) may contribute negatively to the scholastic performance of asthmatic children.

Since no significant difference in scholastic competence was found between the control group and children with nephrotic syndrome, it appears that both groups perceive themselves as equally competent in this area. There may be many reasons for this perception on the part of nephrotic children. The illness and treatment may have fewer effects on the overall cognitive functioning of the child (Coovadia and Loening 1992), and the experience of the illness may not be perceived as traumatic as the other two illnesses under study. The families of children with nephrotic syndrome were found to have a larger coping repertoire and to utilise more resources than the other disease groups. A further important factor is the stability of these families, which may be inferred from their spiritual involvement, and secure relationship with the medical personnel and other support networks. These characteristics may foster an environment conducive to

maintaining adequate competence in many areas, including scholastic abilities.

The findings that the control group scored significantly higher on social acceptance and behavioural conduct than children in each of the illness groups reflect their perceptions of being socially more accepted by their peers and displaying appropriate behavioural conduct in comparison with the three groups of ill children. While these findings indicate that healthy children have higher competencies, they may also reflect the problem areas of children with these diseases. Previous research reveals that ill children (for example, asthmatic children) are at increased risk for psychological problems (MacLean et al. 1992). Mrazek et al. (1985) and Hambley et al. (1989) also reported similar findings of high rates of oppositional behaviour and school-related problems on the part of asthmatic children.

The control group of children scored significantly higher than the leukaemic children on peer relationships, indicating more peer relationships than leukaemic children. Social adjustment difficulties and social skills deficits have been found to occur in childhood cancer patients and may be due to a number of factors related to treatment - for example, changes in their physical appearance, separation from peers as a result of hospitalisation and isolation at home, often resulting in fewer social interaction opportunities (Harper et al. 1985, Harper 1991, La Greca 1992). This may also be true for other chronically ill children.

As school attendance promotes the acquisition of social skills and values necessary for effective interaction with others, absenteeism of the ill child may affect this development. This factor, in addition to the effects of

therapy and treatment, may also account for the self-perception of being different.

Being different from peers may impede the development of appropriate social behaviour and conduct, leading to further social rejection and avoidance by peers (Harper 1991). This interaction has been noted as the "bidirectional interplay between social functioning and disease management" (La Greca 1990 p 290) and is often neglected in clinical management of such children. It was also found that the utilisation of "social support" as a coping strategy may be related to self-worth in children (cf. 6.17). Notwithstanding, the forming of peer relationships is the basis for developing self-worth (including positive social abilities and later self-esteem as an adult) (Bukowski and Hoza 1989).

The control group of children scored significantly higher than the nephrotic and leukaemic children on self-worth. These findings reflect the overall strengths of healthy children in comparison with children in these two illness groups. Thus, children with nephrotic syndrome, like leukaemic children, despite having competencies in the area of school work, do not display high self-worth in comparison with healthy children. This may be due to their self-perceptions of lower competencies described in all the other areas.

Asthmatic children, surprisingly, reveal no significant differences from the control group in self-worth. This finding may reflect the relative resiliency of this group of children. A possible explanation for the lack of difference is that asthmatic children do not experience any changes in their physical appearance as do children in the other illness groups. As asthmatic children also display no significant

differences in frequency of coping strategies from control children, one may infer that in spite of lower perceptions of competencies in the other areas, not all children with chronic illness have problems with self-worth. This finding would seem to support the conclusion of some researchers that well-adjusted children can emerge from both competent and "competent-but-pained families" (Lewis and Looney 1984 p 20). Lewis and Looney (1984) concluded that children may not require an optimal environment and that longitudinal studies may be required to see how these children do over a given period compared with children from optimal families.

An alternate explanation may be a "denial of difficulties" which is common among chronically ill children (Stickland 1978). Harter (1986) found that a process of "distortion" occurs in children's views of their self-worth. Children with high self-esteem take more responsibility for their successes than their failures, slightly inflate their competencies relative to teacher's reports, and value areas of competency in which they excel while discounting areas of lower competency.

These findings appear to substantiate the notion that effective adjustment in the presence of a chronic illness is related to the ability of the individual to develop areas of competency other than those affected by the disability or illness (for example, the self-perception of scholastic competence of children with nephrotic syndrome). Three concepts are helpful in understanding these results. First is the view of Robert White (1965), which places the "experience of efficacy" or competence in the position of a "taproot" of self-esteem. In other words, for the child to maintain his or her self-esteem it is essential that the child maintain areas of competence. Second is the concept of "psychological centrality" (Rosenberg 1979 p 84): The

child's capacity for selective significance or how much value he places on an area of competence, an attribute or on another person's opinion is defined as "psychological centrality." This notion helps to understand how a child suffering from a disease which is marked by unpredictable attacks, or bodily and facial changes and colouring, can maintain an adequate level of self-esteem. The third concept of importance in understanding how the South African Indian child with asthma, maintains adequate self-worth (in the face of the stress experienced by the family), is the notion of "realness" which has been discussed by White (1984) in reference to Black American children. According to White (1984) "The first step of learning to survive is to see life exactly as it is, without self-deception ..." (p 29). Then "...in the face of tragedy ... to keep on climbin' until one has transcended,"... to develop "a healthy respect for life... to be aware of his or her own vulnerability..." (p 30). When a child values the notion of realness and direct experience (that is, gives these notions psychological centrality), chronic illness becomes an aspect of life in which to become stronger. This silent determination, a culturally developed style of coping when faced with stress, may explain how Indian children maintain their self-worth and adjust to their illness.

The clinical implications of the findings obtained may be considered important as certain areas that have been identified for intervention have also been emphasised. The variables which encourage the psychosocial adaptation of children with asthma, leukaemia and nephrotic syndrome may serve to sustain a level of competence against the stress of the illness. These factors may be critical in influencing patterns of positive growth in children who experience a long-term medical stressor. *Comprehensive care should focus on self-esteem, as an aspect of the child's development.*

6.14 Self-Esteem of Chronically Ill and Control Children

The control group children scored significantly higher than the chronically ill group on the dimensions of social acceptance, behavioural conduct and self-worth and marginally significantly higher on scholastic competence, reflecting differences in the self-esteem of chronically ill and control children. Whereas physical appearance was surprisingly not rated lower, academic competence, social acceptance, behavioural conduct and self-worth were lower among chronically ill children than among their healthy counterparts. Thus, physically healthy children indicate that they feel popular and accepted by their peers. They like the way they behave, feel that they do the right things, ensure that their behaviour is within acceptable social norms and indicate that they avoid trouble. They also perceive themselves as having high ability within the realm of scholastic performance. These children also display a higher self-worth than ill children, indicating a happiness within themselves and with their life.

These differences suggest that chronic illness may be associated with children's perceptions of their competencies. As competence also incorporates a sense of control over one's body and environment and is an early task of development, these findings suggest a lack of control by the child as a result of the illness and the continual onslaught of medical stress. Furthermore, there may be difficulty in the stage of self-esteem development. This would be particularly characteristic of the middle-aged child with an emerging sense of independence, a focus on ability and achievements and "esteem by others." There may be an impediment of mastery of skills in the areas examined, because of the limitations posed by illness. Hence, psychological

intervention may be necessary for children suffering from chronic illness. Such intervention may be required to focus on the negotiation of the tasks of the child's self-esteem with each new illness experience thus facilitating self-esteem development and enhancement of its progression from one stage to the next.

The study has also found a relationship between children's self-perceptions of competencies and coping strategies (cf. 6.17); although not conclusive, it is substantial and convincing.

These results also concur with other findings on children's self-worth, which have been lower in children who display poor adjustment to illness (Thompson et al. 1990). The present findings corroborate those which indicate that younger children seem more affected in terms of school tasks and achievements (Rovet et al. 1987). The results are also comparable with the findings from research conducted with other ill children who have reported that peers are awkward around them, that former relationships have to be re-initiated (Barbarin and Chesler 1982) and that treatment has a substantial impact on their peer relationships (Zeltzer et al. 1980). Sillanpaa (1987) and MacLean et al. (1992) have also found relatively high proportions of ill children who display dysfunction in social integration, as well as conduct disorders.

Finally, it seems reasonable to conclude that chronic illness may add incrementally to the development of psychological, behavioural, social and academic competence or adaptation/adjustment problems (Lavigne and Faier-Routman 1992). According to Cadman et al. (1987) approximately 25% to 33% of ill children exhibit psychological and behavioural

problems. This range corresponds roughly to a two-fold increase in the risk estimated in a large epidemiological study of ill children. Self-esteem in children is an important predictor of their overall happiness (Harter 1989). Therefore, the finding of low self-esteem in any group of children would be of concern. However, it is necessary to view the differences obtained not as deficits of chronically ill children but as adaptations to particular person-environmental contexts (Hanson et al. 1990). As argued by Drotar (1981), and later emphasised by Hamlet et al. (1992), in interpreting group differences among ill and healthy children, unique circumstances posed by the chronic illness should be considered.

There "is a lifelong process of adaptation as illness-related stressors and developmental stages give rise to corresponding changes to the child's needs in coping with the chronic illness" (Hamlett et al. 1992 p 35).

6.15 Phase of Illness and Children's Self-Esteem

Children in the induction sub-group rated themselves significantly higher on behavioural conduct. This reflects a perception of conforming behaviour and may be related to the development of a sense of "basic acceptance" (Norem-Hebeisen 1976) in the early years of middle childhood.

There were no other significant differences in the self-perception of competencies or self-worth of children in the induction and remission sub-groups. This may be reflective of a normal developmental process in children.

6.16 Gender and Children's Self-Esteem

The findings that females perceived themselves to have higher scholastic competence and behavioural conduct than males may reflect the societal pressures on girls to display more acceptable and conforming behaviour. This may have resulted in the channelling of their energies into school work. The higher scores of females may also be due to the perception of competencies held by significant others. For instance, teachers' ratings frequently seem to favour females. Kenealy et al. (1988) found that girls scored significantly higher than boys on academic ability, as well as sociability and confidence.

The finding that females have a higher perception of behavioural conduct may reflect the finding that girls display with fewer behavioural problems. This is supported by the finding that boys are referred more for problems with aggression (Achenbach and Edelbrock 1981). Girls are also more compliant (Maccoby and Jacklin 1974) and display greater conformity than boys (Sherman 1971).

The finding that there were no significant differences in self-worth of middle-aged boys and girls suggests that their sense of self may be similar. Maccoby and Jacklin (1974) concluded that there are no gender differences in global self-esteem of healthy children in the early school years. However, Hambley et al. (1989) found that girls who have asthma had lower self-esteem than boys. A reason for this difference may be that the sample included older children. Gender differences in self-esteem may occur as children mature (Burns 1979), beginning in the late primary school years and increasing through adolescence.

6.17 The Relationship between Children's Coping Strategies and Self-Esteem

The coping strategy of "social withdrawal" was significantly associated with the self-esteem of the child. The finding that children who do not utilise the coping strategy of "social withdrawal" had better perceptions of their physical appearance and high self-worth suggests that pro-social behaviour is associated with a higher self-esteem. Therefore, children who display low self-worth may be using a less effective coping strategy, such as "social withdrawal." Such children would consequently require intervention programmes which are designed to enhance prosocial behaviour and the establishment of peer relationships.

Similarly, the marginally significant association between the "social support" coping strategy and self-worth, suggests that children who have high self-worth use a coping behaviour that facilitates supportive interaction.

There was a marginally significant association between the "cognitive restructuring" coping strategy and athletic competence. This finding suggests that the failure to use a cognitive coping technique may be associated with the perception of athletic ability.

Marginally significant associations were also found between the "self-criticism" coping strategy and physical appearance, between "self-criticism" and behavioural conduct, "self-criticism" and social support, and "self-criticism" and self-worth dimensions. The self-criticism coping strategy may, therefore, have important implications for the child's self-esteem. The non-usage of an introspective and critical

attitude appears to be related to children accepting their physical appearance, to an acceptance of their behaviour, and to high self-worth.

Hence, specific coping behaviours may be associated with the self-perception of the competencies of children and their self-esteem. The utilisation of certain coping strategies may, therefore, be related to children's lowered self-perceptions. It is suggested that programmes be designed to enhance the use by children of "social support" and "cognitive restructuring" and to reduce the use of the "social withdrawal" and "self-criticism" coping strategies. The appropriate application of these coping strategies would have positive consequences for the self-esteem of all children, particularly those suffering from asthma, leukaemia and nephrotic syndrome.

6.18 The Relationship between Children's Self-Esteem and Self-Worth

As hypothesised, children's "physical appearance" and "behavioural conduct" were found to be positively correlated with their "self-worth." One may infer that attractiveness and conforming patterns of behaviour in a child are important to his sense of self-worth (Harter 1985). A child's perception of physical attractiveness has special psychological significance for him during childhood. Children have not developed the perceptual defenses and other psychological mechanisms to adequately deal with differential treatment by others as a result of their physical appearance. They have not yet learnt that the differential treatment should not be equated with self-worth (Patzer and Burke 1988). Therefore, "good" physical appearance is considered important, and has been found to influence social acceptance

among children, and popularity by peers (Lerner and Lerner 1977). Also, children tend to equate being good and doing good with being loved or liked, hence the relationship of these two dimensions to self-worth.

The finding that "scholastic competence" was positively associated with "self-worth," suggests that children who feel competent in their school work may have a good sense of self. The findings that "physical appearance" and "behavioural conduct" were positively correlated with "self-worth," suggest that a child's overall sense of worth is associated with physical appearance as well as acceptable behaviour. Clearly these are the domains which many children in middle childhood consider important for their self-esteem. This may also reflect the pressures from many families that children who do well academically and display behaviour patterns acceptable to their communities are considered to have more worth.

It has been suggested that chronically ill children who demonstrate competencies in musical, academic, athletic and other endeavours be encouraged by their parents as a way of building self-confidence and respect (Wells and Schwebel 1987). This aspect of development should be incorporated into the counselling programmes for such families.

6.19 The Relationships between

i) Children's Self-Esteem and Family Resources,

ii) Children's Self-Esteem and Family Health-Related Coping Patterns, and

iii) Children's Self-Esteem and Family Crisis Oriented Coping

The weak associations between children's self-esteem and health-related coping patterns, between children's self-esteem and crisis-oriented coping patterns and children's self-esteem and resources imply that a child's overall self-esteem may be influenced by family coping and resources, although not strongly.

6.20 Additional Data Related to Stress, Resources, Coping and Adaptation

6.20.1 Age of Disease Onset

The finding that there were no significant differences in the stress profile of families with regard to age of disease onset indicates that the stress of caring for a chronically ill child is not related to the age at the time of disease onset.

However, differences occurred in terms of the management of resources, where families whose children presented with early onset (before the age of 4 years) utilised the resources of "family strength II: mastery and health" significantly more than families in the middle disease onset group (after 5 years of age). This indicates a belief in a sense of mastery

of family events and of outcome (such as fate control, flexibility and managerial abilities). The resource also reflects a reliance on family mutuality (emotional support, togetherness and cooperation) between family members and relatives, and physical and emotional health. One reason for the difference in behaviour between parents of children who presented with early disease onset and those whose onset was later, may be the fact that families in the first group, in some instances, have been exposed to a longer duration of the illness and have had more time to adapt. Such families have adjusted physically and emotionally, and are inclined to be flexible rather than rigid in their approach to life. While there is anxiety on the part of these parents, there is also a reliance on family systems and a sense of belief in a good outcome. There is also evidence that the family's ability to change and adjust to the demands of the illness may be predictive of positive outcome (Kazak et al. 1988, Kazak 1989).

The early onset group also scored significantly higher than the middle onset group on the "extended family social support" scale. This reflects family involvement of mutual help and support which is given to and received from relatives. The sharing of burdens, demands, and the responsibilities for management of the illness, with one member outside the family, would contribute to higher functioning of the family (Venters 1981).

The role of social support derived from extended family members also contributes to the day-to-day routine of parents in providing practical information about child-rearing, as well as social and cognitive stimulation to the child (Cochran and Brassard 1979). In this regard, the extended family support functions in much the same way as the traditional extended families did, with parents learning the

task of parenting (Hamlett et al. 1992).

These resources may also reflect the strengths of the Indian family with regard to the stabilising effect of the extended family and social support. While many families live in a nuclear family system, Indian families tend to maintain close ties with the spouses' parents, grandparents, and other relatives as well as older community members. Some families consider a weekly visit to their parents as being obligatory. Here, kinship bonds and the adaptation of family roles, interdependence, collective survival and mutual aid, including a sense of communalism, frequently prevail. These may be some of the coping mechanisms used by Indian families over the generations to adjust to the plethora of pressures faced in their migration to other countries. In the face of socio-cultural, political, economic and illness related stresses, family cohesiveness and structure appear positively related to adaptation.

As previously indicated, the more the "extended family social support" resource is used, the less stress is experienced by families in the area of "occupational limitations." The use of this resource by the family also has implications for coping by children.

Families in the early onset group used "coping patterns I and III" more than families in the middle onset group, reflecting significant differences in the health-coping patterns of the two groups of families. Presumably families in the first group have learnt to cope with chronic illness by reinforcing family harmony and togetherness and by having an optimistic outlook on life and their children's illness. Further actions directed at interfacing with other families in similar predicament, and medical staff and adherence to the

medical regimen are perceived as important. The positive benefits of these two coping patterns have been described earlier.

It may be interpreted that families who have children who develop a serious illness such as leukaemia or nephrotic syndrome in the first four years display behaviour patterns not used by families whose children develop the illness later. This may be an additional reason why families of asthmatic children - asthma may develop after the age of four - display more difficulty adapting to the stress of the illness (cf. 6.21).

Hence, factors such as age of onset, the perceived severity of the condition, - perceived life expectancy, and how the family and child respond (Leventhal 1984) are important in determining the adaptation of families experiencing chronic childhood illness (Pless and Pinkerton 1975, Wallender et al. 1989). However, as the interplay of these factors is complex, the inference of a causal relationship between illness and adaptation responses is cautioned.

The results reaffirm that diagnosis per se is not the only way to assess the needs of the families of chronically ill children, which may be determined by many other factors in the environment. The findings also offer support for considering specific disease variables as being important in the assessment and adaptation of the family to chronic illness (Mullins et al. 1991, Mullins et al. 1992).

6.20.2 Perception of Severity of Symptoms

Maternal perception of the severity of the child's symptoms was significantly related to a high family stress profile. Mothers who perceived their children as displaying more severe "symptoms" of the medical condition scored significantly higher than mothers who perceived their children as having "no symptoms" on 8 of the 15 stress scales, namely: "poor mood/health," "excess time demands," "negative attitude toward index case," "overprotection/dependency," "overcommitment/martyrdom," "physical incapacitation," "lack of activities for index case," "difficult personality characteristics" and marginally higher on "financial problems."

These findings reflect the stress of mothers who perceive their children as experiencing severe "symptoms" of the condition. The parent's subjective response of distress may not change even if the burden of care is lightened (Holroyd 1987). Lazarus and Folkman (1984) are of the opinion that the perception of the strain is more important than its objective occurrence.

Children with "symptoms" were perceived by their mothers as displaying "difficult personality characteristics" more than children with "no symptoms." This scale reflects the responses of mothers to factors such as anxiety, depression, personality or behavioural problems in their ill children, as compared with healthy children. These results are consistent with many researchers (Breslau 1985, Wallender et al. 1989). Indeed, Daniels et al. (1987) have indicated that 20 per cent of ill children, in comparison with 5.4 per cent of a healthy group, were classified as having multiple problems (psychological, physical and behavioural) and who were

believed to be more vulnerable to such problems (Deasy-Spinetta and Spinetta 1980, Stebhens et al. 1983b, Wasserman et al. 1987, Worchel et al. 1988, Wallender et al. 1989). However, behaviours which are adaptive for a chronically ill child may be maladaptive for a healthy child. The child may be rated as displaying problems or psychopathology, when in fact he is behaving in a manner appropriate to the illness. This difference may account for the higher incidence of behavioural problems in chronically ill children (Lewis and Khaw 1982). It has been stated that "... across the entire class of serious illness a modest but consistent support for the relation between disease severity and maladjustment is found" (Barbarin 1990 p 390). Thus, the present results are consistent with previous studies on the co-variation between illness severity and psychological adjustment as they provide support for the view that the illness may be associated with the observed differences between children with chronic illness and healthy children (Stein and Jessop 1982, Wallender et al. 1988, MacLean et al. 1992).

Research has also indicated that the mother's perception or tolerance of her children's behaviour may be affected by her mental status (Brody and Forehand 1986, Breslau et al. 1988). These findings are of particular relevance in studies of families of children with chronic illnesses because of the high rate of maternal depression reported (Breslau et al. 1982). The finding of "poor mood/health" on the part of the mother (cf. 6.2.1.1) may be an additional factor when considering the reported incidence of difficult behaviour in children with chronic illnesses.

In view of the stress experienced by mothers who perceive their children to be ill, the question is whether these families have the necessary resources and competencies to assist them in their adaptation to chronic childhood illness.

The findings indicate that families who perceive their children to have "no symptoms" in comparison with families who view their children as having "symptoms," manage resources differently. Families who perceive their children to be well were found to utilise the "family strength I: esteem and communication" resource, reflecting the presence of family esteem, communication and mutual sharing, and encouragement of autonomy among its members. "Financial" sufficiency also has been reported by these families. The health status of the child may also determine employment issues on the part of both parents, thereby contributing to financial strength.

Unlike families who perceive their children as having "symptoms," those who perceive their children to have "no symptoms" utilised "coping pattern I" aimed at maintaining family integration, cooperation and an optimistic definition of the situation. These families cope by maintaining an integrated and harmonious family life, and an optimistic view of life. This group of families also used "coping pattern II" more than families who perceive their children as having "symptoms." Parental use of efforts directed at activities to enhance self-esteem, the maintenance of social support and psychological stability are associated with their adaptability. The positive benefits of self-esteem and social support have been emphasised earlier.

Families who perceive their children to be well display better resources and coping patterns than families who perceive their children as having more severe physical symptoms. The latter group may benefit from education about the condition, as well as from social and psychological support. The children who are perceived as manifesting physical symptoms of the diseases under discussion also require intervention by mental health personnel in an effort

to enhance development in different areas. This again points to the lack of psychosocial intervention programmes for families of physically ill children.

6.20.3 Perceived Life Expectancy

Not surprisingly, the family's perception of the life expectancy of their child was significantly related to the stress experienced, and to the resources and coping patterns used.

Significant differences were also observed between the stress profiles of families who have children with normal life expectancy and those having children with an uncertain outcome. Stress was significantly higher in families of children with uncertain prognosis on 11 of the 15 stress scales, namely: "poor health/mood," "excess time demands," "negative attitude toward index case," "overprotection/dependency," "overcommitment/martyrdom," "pessimism," "limits of family opportunity," "physical incapacitation," "occupational limitations," "social obtrusiveness," and "difficult personality characteristics." Thus, in addition to displaying a similar stress profile as families who perceive their children as displaying "symptoms," families who perceive their children as having an "uncertain" outcome display "pessimism," reflecting an expectation that the child's condition may worsen, and that the family and child will be more burdened in the future.

Families who perceive their children as having an "uncertain outcome" also scored higher on "social obtrusiveness" than families in the "normal expectancy" group. This scale reflects the belief that the primary caretaker is the only

person able to care for the ill child, and she obtains a sense of self-worth from her obligations. The behaviour may be related to the mother's desire to do all she can for the child while he lives.

There were no significant differences in management of resources between families who have children with normal life expectancy and those having children with an uncertain outcome. However, families who perceive their children as having a normal life span scored marginally higher on the social desirability scale, reflecting a perception that such families view a good prognosis as socially desirable.

The finding that there were no significant differences in the coping patterns of families who perceive their children as having an "uncertain outcome" and those who believe they have a "normal expectancy" suggests similar coping behaviours. However, the coping patterns and resources utilised by families who are unsure of their children's outcome may not be adequate in view of the stress experienced. Such families may be considered a high risk group and warrant psychological support.

6.20.4 Maternal Education

Maternal education was found to be an important factor in the stress profiles of families. Mothers who had only primary school education scored significantly higher than mothers who had received a high school education on 10 of the 15 stress scales (namely: "poor mood/health," "negative attitude toward index case," "overprotection/dependency," "overcommitment/martyrdom," "pessimism," "lack of family integration," "limits on family opportunity," "financial

problems," "lack of activities for index case" and "difficult personality characteristics"). These findings are partly consistent with those of other researchers (Anthony and Cohler 1987, Wallender et al. 1989). However, Japanese mothers who were less educated appeared less distressed than educated mothers in their roles of caring for a disabled child (Inanami et al. 1980). Of course, socio-cultural factors may be more relevant than educational level per se.

Mothers with less education experienced greater stress not only in personal areas, but within the family system and in caring for the ill child. This may be due to the limited repertoire of coping skills of mothers with a lower educational level. More importantly, these mothers also experience a lack of family integration, suggesting lack of cohesiveness in the family system.

The finding of significant differences between mothers with primary and secondary school education on the "financial well-being" and "sources of financial support" scales reveal that mothers with a higher level of schooling enjoyed better financial resources. As previously discussed, it is likely that mothers who have a higher education are able to command better-paid employment, expand their financial support resources, and are more able to socialise or get out of the home to relieve themselves of the stress associated with the child's illness. Mothers with a higher education also have higher self-esteem (Buehler et al. 1986), which would facilitate the creation of a positive family environment and adaptation of all family members.

Unlike mothers who had only primary school education, those with secondary schooling also utilised "coping pattern III" aimed at understanding the health care situation through

communication with other parents and consultation with the health care team. Hence, a higher level of education is associated with a more appropriate health-related coping behaviour.

Mothers with secondary school education also utilised the coping strategy of "mobilising family to acquire and accept help" more than mothers who had only a primary level of education. This suggests that mothers with a higher educational status employ a behaviour aimed at promoting the family's efforts at seeking professional counselling, medical assistance and community support. Lack of such support has been associated with distress among parents (Kazak et al. 1988, Speechly and Noh 1992). Propst et al. (1986) have indicated that higher educational level was a significant predictor of both lower anxiety and a subjective perception of coping more effectively. *Thus, mothers with a poor educational status, and who experience low levels of support should be considered for supportive intervention.*

Maternal education may, therefore, be associated with adaptation to chronic childhood illness.

6.20.5 Medical Knowledge

The finding that families who have no medical knowledge of the child's condition scored significantly higher on the "lack of activities for the index case" than families who have medical knowledge suggests that such families would benefit from programmes designed to emphasise the specific condition and relevant restrictions, if any, placed on the child.

Mothers of leukaemic and nephrotic children felt that they had acquired knowledge and understanding of their child's medical condition. Having medical knowledge or having been informed of the condition by the doctors treating the child was rated highly by mothers of nephrotic children (81.82 per cent), followed by 78.26 per cent of mothers of leukaemic children. These findings are consistent with studies on families of children with cancer (Zeltzer et al. 1984a, Zeltzer et al. 1984c). These two groups also have better resources and coping behaviours, as discussed earlier.

Only 56.67 per cent of mothers of asthmatics children believed they were well-informed about their children's condition. One explanation for this may be the difficulty in comprehending a condition which has an erratic character. The pathophysiology of asthma may be more nebulous and confusing to parents as compared with the other two conditions, which appear more concrete when explained by health professionals. Parental worry and fear about asthma have been related to the knowledge the family had about the condition (Carswell et al. 1990). Schlebusch (1990) has suggested that effective communication and information not only enhances patient self-care, but also treatment outcome of the condition.

Knowledge of the child's condition was also found to be associated with family resources. Families in the "knowledge" group utilised the "family strength I: esteem and communication" resource significantly more than families who had no knowledge of the child's condition. This finding suggests that having knowledge of the medical condition would influence families in their ability to maintain problem-solving behaviours, communication, and optimism, thereby demonstrating its positive effect.

Families in the "knowledge" group scored significantly higher on the "financial well-being" resource than families who do not have medical knowledge. This implies that parents who are financially secure are more educated and feel the need to enquire more about their child's condition. Parents who are informed have a better understanding of the condition, and may continue in their employment. A more knowledgable parent may not visit the hospital unnecessarily, reducing their medical costs.

The finding that families who have medical knowledge of the condition scored significantly higher on the "social desirability" resource than families who do not have medical knowledge suggests that such families may be able to perceive the situation as being socially more acceptable, particularly to other people. Such behaviour may improve the family's adaptation to the illness. This finding is congruent with that of Blotcky et al. (1985) who found that knowledge of the condition and coping are related to a decreased level of subjective distress.

There were no significant differences in the health-related coping patterns of families with and without medical knowledge, suggesting that both groups cope similarly.

Families who had "knowledge" used the family-oriented coping strategy of "mobilising family to acquire and accept help" more than families who had "no knowledge." This once again corroborates the view that the relaying of appropriate medical information may enhance the family's coping efforts in seeking professional counselling and medical consultation, as well as an acceptance of support from community systems and resources.

Hence, the information the family has about the chronic condition has implications for family coping with illness, being an important factor in the maintenance of family adaptation (Koocher and O'Malley 1981, Carswell et al. 1990).

It should be noted, however, that the present findings may be biased since the "poor knowledge" group comprised families of asthmatics, who were of a lower socio-economic strata.

6.21 Additional Data Related to Children's Coping Strategies and Self-Esteem

6.21.1 Age of Disease Onset

Interestingly, the age of disease onset was related to the use of certain coping strategies by children. Children whose disease began in the first four years scored marginally higher on the "social withdrawal" coping strategy than children whose disease began in middle childhood, suggesting that early illness onset may be associated with children's coping in respect of social behaviour. It could also be inferred that the long duration of the illness does not necessarily imply positive adaptation of the child.

The finding that children whose disease began in middle childhood used "distraction" marginally more than children whose disease began earlier indicates the possibility that the effective coping skill (which may have developed earlier in childhood) would continue to be used. This group of children also scored significantly higher on social acceptance and self-worth. These findings suggest that children whose illness began later have probably had

sufficient time to acquire certain effective coping skills, learn how to establish peer and social relationships, and develop a higher social esteem and self-worth. The finding that significantly higher self-worth was noted in the group of children whose illness occurred in middle childhood reaffirms the view that the self-esteem and self-worth structures develop in the earlier years (Freud 1965, Cotton 1983). Children in whom chronic illness developed after the age of five years are happier within themselves and with their life. They have had time to acquire the necessary ingredients for the development of self-worth.

Thus, the occurrence of a serious illness in the first four years of a child's life may have a negative association with a child's overall self-worth, and outlook on life. Psychological intervention is, therefore, more strongly indicated in young children who develop chronic illness during the earlier years of their development.

6.21.2 Perception of Severity of Symptoms

Children who were perceived by their mothers as manifesting the symptoms of their condition were found to utilise "social withdrawal" significantly more than children whose mothers perceived them as having no symptoms. This suggests that children who are perceived to be severely ill tend to withdraw from people. However, as children with chronic illness have been found to exhibit socially withdrawn behaviour, it is more than probable that children who are perceived as displaying symptoms of their illness cope in this manner.

"Social acceptance" was significantly higher in children who were perceived as healthy with "no symptoms" than children who were perceived as having "symptoms," reaffirming that healthy children do feel popular and are more accepted by their peers than ill children. In this regard, research on psychological adjustment and illness severity has shown that children with severe illness may have lower levels of psychological adjustment (Perrin et al. 1989).

There were no other significant differences in the children's competencies in relation to the perceived severity of the condition. This is not surprising when interpreted according to the notion of "psychological centrality" (Rosenberg 1979, Harter 1984), where a child with a severe disease will realistically assess the limitations of his or her illness and develop areas of competence which do not involve these limited areas.

6.21.3 Perceived Life Expectancy

Children who were thought to have an uncertain life expectancy scored marginally higher on the "resignation" coping strategy than those who were expected to have a normal life expectancy. Such coping behaviour indicates that children who live in an environment faced with doubt as to how long they would live would find it easier to adapt to their illness by giving up or passively accepting their fate.

There were no significant differences in the self-esteem of children in the uncertain or normal life expectancy groups. This indicates that perceived prognosis of the child's life outcome may not be associated with his self-esteem. This information has ramifications for the development and

sustenance of self-esteem in children with conditions such as asthma, leukaemia and nephrotic syndrome.

6.22 Conclusion

The contribution of the present study has been to offer empirical data on the stresses experienced by families who have children suffering from the chronic illness conditions of asthma, leukaemia, and nephrotic syndrome. Of clinical significance is the finding that certain groups of families are able to maintain familial competencies by utilising resources and coping patterns which are specifically related to the alleviation of stress associated with the illnesses. This suggests that psychosocial adaptation and competent functioning is possible when certain coping skills and resources are available and implemented.

A further contribution is the identification of coping strategies and self-esteem of children who have asthma, leukaemia and nephrotic syndrome, particularly when compared with the control group. The study also identified coping strategies and dimensions of self-esteem which encourage self-worth in children. Also of importance is the relationships between family coping and resource management and children's coping, and children's coping and their self-esteem.

6.23 Clinical Implications

Biomedical research has extended the lives of chronically ill children. In response, psychologists in First World countries have developed programmes to attenuate the side

effects of treatment. However, "professional training ... has not kept pace with the changing needs of families with chronically ill children; they do not grow over time with the illness" (Hobbs et al. 1985 p 57). Hospitals in Third World countries appear to lack the resources to provide such routine psychological service to children.

The findings obtained in this investigation validate the importance of psychological intervention in the comprehensive care of children and families with asthma, leukaemia and nephrotic syndrome. Based on the results of the present study, a number of recommendations may be incorporated into a treatment programme for chronically ill children and their families. The findings underscore the following:

- Information about the disease should be conveyed by health personnel to families experiencing chronic illness, at a level comprehended by them.
- Information concerning the child's development and maturation should be provided.
- Open communication on the part of medical personnel treating the ill child and his family is emphasised, since this study points to increased competency in coping and resource management on the part of families as a result of such practice.
- Intervention could assist parents in distinguishing global stressors from specific stressful situations, with an emphasis on areas that could be changed.
- Instruction in the use of certain coping patterns, strategies and the management of certain resources, which have been found to be associated with a decrease in stress (such as, coping pattern I, II, III, social, extended, family support and the learning of problem-solving techniques), are critical for families of chronically ill children.

- Ideally, both parents should be involved in the care of the ill child. Communication, emotional expressiveness, division of labour and mutual support are among the characteristics that could decrease the stressors experienced.
- As certain coping strategies are effective for the psychological functioning of children (for example, distraction, social support, cognitive restructuring, emotional regulation, problem-solving), the teaching of such skills to chronically ill children is recommended.
- Intervention should also focus on assisting parents in managing their ill children's psychosocial problems. This may enhance self-esteem development in chronically ill children.

6.24 Limitations of the Study

Certain limitations have been identified during the course of this study. Firstly, fathers have not participated in the investigation. The responses of fathers could enable a two-parent comparison of adaptation. The inclusion of data from other family members is also potentially important.

Secondly, the sample size of the study may be considered small. While the sample fulfils the statistical requirements for research analysis, and examines many variables (Koocher, personal communication), the present study was restricted by the scarcity of children with these specific illnesses. A larger sample may increase the reliability of the results. There was also a very small sample of girls in the study, making comparisons by gender anything but tentative.

Thirdly, a large battery of tests was used in the present study. While every care was taken to avoid testee fatigue, the number of tests could be reduced in future research.

Fourthly, the sample of mothers of asthmatic children were found to experience social problems that were not necessarily related to the illness. This factor could be controlled in future research.

6.25 Suggestions for Future Research

While the present study focused on the assessment of an Indian sample, a focus of future research could be the examination of differences in the resources, coping and adaptation of other cultural and ethnic groups. As South Africa presently faces many socio-political stresses, it is important to examine this facet of the illness. It is also crucial to know how chronically ill children and families from more deprived communities cope with their conditions.

The need for future research to establish those factors which are most effective in developing and sustaining competence in families of chronically ill children has been underscored by this study. It may, therefore, be of clinical interest to replicate these findings in hospitals serving patients from different geographic locations, and with different demographic characteristics. Further work applying the resiliency model to different illness groups may also be of clinical and therapeutic value.

The need for the validation of other family and child coping and adaptation measures specific to chronic illness and

developed for Third World populations is vital. In the face of the increasing number of children suffering chronic illness, research in this area is essential, particularly if health professionals are to ensure successful coping, self-esteem development and adaptation of children in society. The identification of family patterns of coping and adaptation most conducive to developing a healthy self-esteem in chronically ill children, and successful social and family relationships need to be emphasised.

Longitudinal studies are also indicated to assess child and family coping and adaptation over time, and during the different periods of development.

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APPENDIX A

BIOGRAPHICAL QUESTIONNAIRE
PARENT

A. DATE OF ASSESSMENT: .....
NAME: .....
AGE: .....

Kindly place a tick ✓ in the appropriate box ❑

1. RELATIONSHIP TO CHILD:

❑ mother ❑ caregiver

2. RELIGION:

❑ moslem ❑ hindu ❑ christian ❑ other

3. CURRENT MARITAL STATUS:

❑ single ❑ married ❑ divorced ❑ widowed

4. OCCUPATION:

❑ unemployed ❑ housewife ❑ skilled ❑ unskilled ❑ professional

5. EDUCATION:

❑ none ❑ <Std.3 ❑ Std 3-4 ❑ Std 5-6 ❑ Std 7-8 ❑ Std 9-10 ❑ >Std.10

6. FAMILY INCOME:

_____ per month

B. LIVING ARRANGEMENTS

1. FAMILY LIVES WITHIN:

❑ nuclear family ❑ extended family

2. FATHER RESIDES WITH FAMILY:

❑ yes ❑ no

C. CULTURAL FACTORS

1. Have you sought assistance from a priest for the illness?

❑ yes ❑ no

2. Have you carried out a prayer/ceremony to assist in improving the illness?

❑ yes ❑ no

3. Do you believe that illness is a punishment form God?

❑ yes ❑ no

4. Do you sometimes feel you are you blame for your child's illness?

❑ yes ❑ no

D. PARENT'S IMPRESSION

1. Has the illness brought you closer to your spouse?

❑ yes ❑ no

2. Has the illness caused marital problems?

❑ yes ❑ no

3. Has your child's relationships changed during the course of the illness?

❑ yes ❑ no

4. Has there been a change in his/her school performance?

❑ yes ❑ no

5. How would you describe your child's school performance?

❑ below average ❑ average ❑ above average

6. Is your child more frequently absent from school?

❑ yes ❑ no

7. How would you describe your child's behaviour?

❑ withdrawn ❑ behaviour problem ❑ dependent

❑ attention seeking ❑ no change

E. SEVERITY OF SYMPTOMS

My child has

1. No symptoms, and is lot limited in physical activity. ❑
2. Symptoms after exercise,/exertion, and is slightly limited in physical activity. ❑
3. Symptoms with ordinary activity, in which he/she is markedly limited ❑.
4. Symptoms even at rest, and is unable to engage in any physical activity without increasing discomfort. ❑

F. PROGNOSIS

In my opinion, the outlook for my child is

1. normal life expectancy ❑
2. uncertain but hopeful ❑
3. uncertain but not hopeful ❑
4. progression of disease and relapse ❑

G. MEDICAL KNOWLEDGE

Do you feel that you have adequate medical knowledge about your child's condition?

❑ yes ❑ no

PART II

BIOGRAPHICAL QUESTIONNAIRE
CHILD

1. HOSPITAL O.P.D. NO.....
2. NAME: .....
3. SEX : ❑ Male ❑ Female
4. AGE : .....
5. ILLNESS TYPE: .....
6. AGE OF ONSET OF ILLNESS: .....
7. NUMBER OF ADMISSIONS TO HOSPITAL IN THE LAST 12 MONTHS: .....
8. ATTENDS SCHOOL:
   ❑ yes ❑ no
9. PRESENT CLASS AT SCHOOL:
   ❑ Cl.1 ❑ Cl.2 ❑ Std.1 ❑ Std.2 ❑ Std.3 ❑ Std.4
10. PEER GROUP ATTACHMENT:
    ❑ yes ❑ no
11. CLOSE FRIEND:
    ❑ yes ❑ no

APPENDIX B

KIDCOPE

	Did you do this?		How much did it help?		
1. I just tried to forget it.	yes	no	Not at all	A little	A lot
2. I did something like watch T.V. or played a game to forget it.	yes	no	Not at all	A little	A lot
3. I stayed by myself.	yes	no	Not at all	A little	A lot
4. I kept quiet about the problem.	yes	no	Not at all	A little	A lot
5. I tried to see the good side of things.	yes	no	Not at all	A little	A lot
6. I blamed myself for causing the problem.	yes	no	Not at all	A little	A lot
7. I blamed someone else for causing the problem.	yes	no	Not at all	A little	A lot
8. I tried to fix the problem by thinking of answers.	yes	no	Not at all	A little	A lot
9. I tried to fix the problem by doing something or talking to someone.	yes	no	Not at all	A little	A lot
10. I yelled, screamed, or got mad.	yes	no	Not at all	A little	A lot
11. I tried to calm myself down.	yes	no	Not at all	A little	A lot
12. I wished the problem had never happened.	yes	no	Not at all	A little	A lot

13. I wished I could make things different.	yes	no	Not at all	A little	A lot
14. I tried to feel better by spending time with others lot like family, grownups, or friends.	yes	no	Not at all	A little	A
15. I didn't do anything because the problem couldn't be fixed.	yes	no	Not at all	A little	A lot

APPENDIX C

THE SELF-PERCEPTION PROFILE
WHAT I AM LIKE
(Child)

Now I am going to read pairs of sentences to you about things kids like to do and the way kids feel or act. In each case, I want you to tell me which of the two sentences is more like you. Let's begin with an example. (CIRCLE THE NUMBER MOST LIKE THE CHILD).

Really True for me	Sort of True for me				Sort of True for me	Really True for me
a. 1	2	Some kids would rather play outdoors in their spare time	BUT	Other kids would rather watch T.V.	3	4
1. 1	2	Some kids feel that they are very good at their school work	BUT	Other kids worry about whether they can do the work assigned to them	3	4
2. 1	2	Some kids find it hard to make friends	BUT	For other kids it's pretty easy	3	4
3. 1	2	Some kids do very well at all kinds of sports	BUT	Other's don't feel that they are very good when it comes to sports	3	4
4. 1	2	Some kids are happy with the way they look	BUT	Other kids are not happy with the way they look	3	4
5. 1	2	Some kids often do not like the way they behave	BUT	Other kids usually like the way they behave	3	4
6. 1	2	Some kids often get mad at themselves	BUT	Other kids are pretty pleased with themselves	3	4
7. 1	2	Some kids feel like they are just as smart as other kids their age	BUT	Other kids aren't so sure and wonder if they are as smart	3	4
8. 1	2	Some kids have alot of friends	BUT	Other kids don't have very many friends	3	4

9. 1	2	Some kids wish they could be alot better at sports	BUT	Other kids feel they are good enough at sports	3	4
10. 1	2	Some kids are happy with their weight and height	BUT	Other kids wish their weight or height were different	3	4
11. 1	2	Some kids usually do the right thing	BUT	Other kids often don't do the right thing	3	4
12. 1	2	Some kids don't like the way they are leading their life	BUT	Other kids do like the way they are leading their life	3	4
13. 1	2	Some kids are pretty slow in finishing their school work	BUT	Other kids can do their school work quickly	3	4
14. 1	2	Some kids are are kind of hard to like	BUT	Other kids really easy to like	3	4
15. 1	2	Some kids think they could do well at just about any new outdoor activity they haven't tried	BUT	Other kids are afraid they might not do well at outdoor things they haven't ever tried	3	4
16. 1	2	Some kids wish their body was different	BUT	Other kids like their body the way it is	3	4
17. 1	2	Some kids usually act the way they know they are supposed to	BUT	Other kids often don't act the way they are supposed to	3	4
18. 1	2	Some kids are happy with them-selves most of the time	BUT	Other kids are often not happy with themselves	3	4
19. 1	2	Some kids often forget what they learn	BUT	Other kids can remember things easily	3	4

20. 1	2	Some kids are always doing things with alot of kids	BUT	Other kids usually do things by themselves	3	4
21. 1	2	Some kids feel that they are better than others their age at sports	BUT	Other kids don't feel they can play as well	3	4
22. 1	2	Some kids wish their physical appearance was different	BUT	Other kids like their physical appearance the way it is	3	4
23. 1	2	Some kids usually get in trouble because of things they do	BUT	Other kids usually don't do things that get them in trouble	3	4
24. 1	2	Some kids like the kind of person they are	BUT	Other kids often wish they were someone else	3	4
25. 1	2	Some kids do very well at their classwork	BUT	Other kids don't do very well at their classwork	3	4
26. 1	2	Some kids wish that more kids liked them	BUT	Other kids feel that most kids do like them	3	4
27. 1	2	In games and sports some kids usually watch instead of play	BUT	Other kids usually play rather than watch	3	4
28. 1	2	Some kids wish something about their face or hair looked different	BUT	Other kids like their face and hair the way they are	3	4
29. 1	2	Some kids do things they know they shouldn't do	BUT	Other kids hardly ever do things they know they shouldn't do	3	4
30. 1	2	Some kids are very happy being the way they are	BUT	Other kids wish they were different	3	4

31. 1	2	Some kids have trouble figuring out the answers in school	BUT	Other kids almost always can figure out the answers	3	4
32. 1	2	Some kids are popular with others their age	BUT	Other kids are not very popular	3	4
33. 1	2	Some kids don't do well at new outdoor games	BUT	Other kids are good at new games right away	3	4
34. 1	2	Some kids think that they are attractive or good looking	BUT	Other kids think that they are not very attractive or good looking	3	4
35. 1	2	Some kids are usually very kind to others	BUT	Other kids wish they can be kinder to others	3	4
36. 1	2	Some kids aren't very happy with they way they do a lot of things	BUT	Other kids think they way they do things is fine	3	4